A MIXED-METHOD STUDY EXPLORING THE EXPERIENCES OF ADULTS WITH AUTISM AND CO-EXISTING MENTAL HEALTH DISORDER(S), AND PROFESSIONALS' KNOWLEDGE OF AUTISM SPECTRUM DISORDER (ASD)

CHELSEA ERICA COURTS

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Abstract

Adults with autism are at high risk of experiencing mental health difficulties. It is therefore surprising that very little is known about the needs and experiences of this population in relation to accessing adult mental health services. This study had three aims: (1) to explore the needs and experiences of adults with co-existing autism and mental health disorder, (2) to establish whether a Health Board's adult mental health services met the needs of these service users, and (3) to evaluate the knowledge of ASD amongst mental health professionals working within adult mental health services.

This study utilised a parallel mixed-method design, consisting of two-phases of data collection. The first phase involved semi-structured interviews with adults with co-existing autism and mental health disorder(s) to explore their needs and experiences of accessing adult mental health services (N = 20). The second phase involved an online questionnaire to establish professionals' knowledge of ASD, as well as the confidence that professionals had in their ASD knowledge (N = 58).

The qualitative interviews from Phase 1 were analysed using Interpretative Phenomenological Analysis (IPA). Five superordinate themes were identified relevant to the needs and experiences of service users with co-existing autism and mental health disorder(s): (1) Experience of Autism Diagnosis, (2) Staff Awareness of Autism, (3) Facilitating Communication, (4) Dissatisfaction, and (5) Making Accommodations. The quantitative findings from Phase 2 indicated that mental health professionals may not possess adequate levels of ASD knowledge. Additionally, ASD knowledge held by professionals who had undertaken ASD training was significantly higher than those who had not received training, indicating that providing ASD training could be a means to increasing professionals' ASD knowledge.

The current study contributed to knowledge in the following ways: (1) it explored the experiences of adults with co-existing autism and mental health disorder(s) and identified the service needs of this population, (2) it established the current level of ASD knowledge and ASD confidence held by mental health professionals working in an adult mental health service, and (3) it resulted in the development of a questionnaire that can measure individuals' ASD knowledge and ASD confidence.

Recommendations for practice generated from the findings of the current study include a need for a clear and consistent pathway for autism diagnosis. Staff working within adult mental health services need to be provided with autism training, with staff also needing to ensure that they ask service users about their communication preferences. Mental health services need to move away from a crisis-driven provision to a service that works proactively to prevent mental health decline. A need for the Crisis Team to modify the way they currently provide support to the current population was evident as well as a need for healthcare environments to be accessible to adults with autism. Recommendations for future research are also provided within this thesis.

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Author's Declaration

This is to certify that, except where specific reference is made, the work described in this thesis is the result of my own research. Neither this thesis, nor any part of it, has been presented, or is currently submitted, in candidature for any other award at this or any other University.

Signed: .....*C.E.Courts*.....

Date: .....*20/07/2021*.....

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Abbreviations

ADHD	Attention Deficit Hyperactivity Disorder
AMHS	Adult Mental Health Services
ANOVA	Analysis of Variance
APA	American Psychological Association
ARC	Assisting Recovery in the Community
ASD	Autism Spectrum Disorder
ASSIA	Applied Social Sciences Index and Abstracts
BME	Black and Minority Ethnic
BPD	Borderline Personality Disorder
BPS	British Psychological Society
CAMHS	Child and Adult Mental Health Services
CASP	Critical Appraisal Skills Programme
CBPR	Community Based Participatory Research
CBT	Cognitive Behavioural Therapy
CINAHL	Cumulative Index to Nursing and Allied Health Literature
CMHT	Community Mental Health Team
CRHTTs	Crisis Resolution and Home Treatment Teams
CTP	Care and Treatment Plan
DASPA	Drug and Alcohol Single Point Access
DSM	Diagnostic and Statistical Manual of Mental Disorders
ESR	Electronic Staff Record
GAD	Generalised Anxiety Disorder
GMC	General Medical Council
GP	General Practitioner
HCRW	Health and Care Research Wales
HRA	Health Research Authority
ICD	International Classification of Diseases
IPA	Interpretive Phenomenological Analysis
IQ	Intelligence Quotient
IRAS	Integrated Research Application Systems
LD	Learning Disability

MDD	Major Depressive Disorder
MDT	Multi-Disciplinary Team
NHS	National Health Service
NHSX	National Health Service X
NICE	National Institute for Health and Care Excellence
OBGYN	Obstetrics and Gynaecology
OCD	Obsessive Compulsive Disorder
PhD	Doctor of Philosophy
PDD	Persistent Depressive Disorder
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-Analysis
PTSD	Post-Traumatic Stress Disorder
RCN	Royal College of Nursing
REC	Research Ethics Committee
SAT	Specialist Autism Team
SPSS	Statistical Package for Social Services
STOMP	Stopping Over Medication of People with a Learning Disability, Autism or Both
UK	United Kingdom
UPIAS	Union of the Physically Impaired Against Segregation
USW	University of South Wales
WHO	World Health Organisation
YFC	Youth and Family Centre

Terminology

As noted by Fletcher-Watson and Happé (2019), there is currently great debate in regard to the language that is used to describe autism between person-first (person with autism/ASD) and identity-first language (autistic person). Kenny et al. (2016) explored people's opinions about how autism is described, and found that of the adults with autism in their sample, 61% endorsed using the term 'autistic', with only 28% endorsing the term 'person with autism'. However, when asked to rate their preference on a likert scale of terms used to describe autism, both 'autistic person' and 'person with autism' obtained a mode score of 4, with a score of 4 meaning that adults with autism liked the use of these terms when describing themselves or referring to a person with autism.

In addition to the above debate, there has been disagreement over the use of the word 'disorder' within Autism Spectrum Disorder (ASD) with many people arguing that this implies abnormality, rather than autism being seen as a natural variation in the human population (Fletcher-Watson and Happé, 2019). However, it could be contended that those with autism who are most impaired may consider autism to be a disorder, whereas those who are impaired to a lesser degree may not share this view. Some people prefer to use the term autism spectrum conditions as an alternative way to refer to autism as it avoids the negative connotations of the word 'disorder' (National Autistic Society, 2018). Another term used in relation to autism, and other neurodevelopmental disorders, is neurodiversity. Neurodiversity is the concept that individuals have brain-based differences and that this is part of natural variation, and should be viewed as such (Purkis, Goodall and Nugent, 2016). In summary, a main argument from the neurodiversity movement is the idea that neurodivergent people are different, not less (Purkis, Goodall and Nugent, 2016).

To respect the views of the participants with autism who took part in the current study, participants were asked at the beginning of the study which terminology they preferred: person with autism/ASD or autistic person. The outcome of this was that 'person with autism/ASD' was the preferred term and therefore, person-first terminology has been utilised throughout this thesis. Additionally, 'person with autism' has been favoured over 'person with ASD' to avoid any negative perceptions associated with the word

‘disorder’. However, there are some instances where it has been more appropriate to use ‘ASD’, such as sections specifically exploring the diagnostic criteria of ASD (and co-existing conditions). Additionally, ‘ASD’ has been used instead of ‘autism’ in relation to Phase 2 of the study, which specifically measured professionals’ ASD Knowledge and ASD Confidence.

Chapter One: Introduction

1.1 Overview

The first chapter of this thesis introduces the concept of mental health, defining both mental health and mental disorder, before highlighting the increased prevalence of mental health conditions in adults living with autism. The study aims and a study overview will then be provided. Following this, there will be a brief discussion of the study's originality and contribution to knowledge, as well as the importance of reflexivity in research which will be followed by the research student's pre-data collection reflexive statement. This chapter concludes by providing a summary of the content of each chapter contained within the current thesis.

1.2 Background

1.2.1 Defining mental health

Mental health is known to be a priority health issue; one in four people experience mental health difficulties in their lifetime, with one in six people experiencing symptoms of mental illness at any one time (Welsh Government, 2012). But mental health is more than the absence of mental disorder/disabilities; mental health is a fundamental part of health (World Health Organisation, 2018). The World Health Organisation (2018) contends that there can be no health without mental health as health is a state of total physical, mental and social wellbeing. Mental health affects our ability to think and function, and the way we act and interact with others, affecting all aspects of life including work and life satisfaction. The World Health Organisation (WHO; 2018, para. 2) defines mental health as a "state of well-being in which an individual realises his or her own abilities, can cope with the normal stresses of life, can work productively and is able to make a contribution to his or her community". Galderisi et al. (2015) expanded the above definition of mental health utilised by the WHO. Their definition goes as follows:

> *"Mental health is a dynamic state of internal equilibrium which enables individuals to use their abilities in harmony with universal values of society. Basic cognitive and social skills; ability to recognize, express and modulate one's own emotions, as well as empathize with others; flexibility and ability to*

> *cope with adverse life events and function in social roles; and harmonious relationship between body and mind represent important components of mental health which contribute, to varying degrees, to the state of internal equilibrium".* (Galderisi et al., 2015, p.231)

This definition is helpful as it clarifies any misunderstandings that may exist such as a belief that positive feelings and positive functioning are essential for good mental health (Galderisi et al, 2015). The above definition acknowledges that people may experience appropriate negative emotions (such as sadness, anger, fear, and grief) whilst at the same time having the necessary resilience required to restore the dynamic state of internal equilibrium (Galderisi et al, 2015). Additionally, individuals who may not work productively, and therefore may be prevented from contributing to their society (e.g. individuals with physical disabilities and individuals of a certain age), can still have good mental health.

Now that mental health has been considered, mental disorder will now be defined. According to WHO (2019a), mental disorders are conditions that consist of a combination of "abnormal thoughts, perceptions, emotions, behaviours and relationships with others" (para. 1). Mental disorder/mental illness is associated with distress and/or problems with functioning in social and occupational activities (American Psychiatric Association, 2018). It is known that an individual's mental health exists on a continuum and is variable (Johnson, 2019); equally, mental illnesses can vary in severity from mild to severe, with more severe mental disorder generally requiring more support/intervention. Treatment may be provided to individuals who have experienced poor mental health for a prolonged period of time, or to individuals who have reached a crisis point before seeking support (Johnson, 2019). The sooner that mental health difficulties are identified, the better it is for the individual, for many mental health problems will persist without intervention. WHO (2019a) argued that accessing healthcare that is capable of providing treatment/support for mental disorders is crucial for individuals living with mental health conditions.

1.2.2 Mental health disorders in autism

Autism, which will be discussed in greater detail in the following chapter, is a neurodevelopmental disorder with a prevalence of approximately 1% (APA, 2013) that can be described as a "severe disorder of communication, socialisation and

imagination" (Fletcher-Watson and Happé, 2019, p.9). Research demonstrates the risk of mental health problems to be higher for individuals with autism, with research showing that nearly four in five (79%) meet the diagnostic criteria for at least one psychiatric disorder during their lifetime (Lever and Geurts, 2016). Due to the higher likelihood of mental illness in people with autism, people with autism are potentially more likely to require support from mental health services. Therefore, it is important to ensure that mental health services are delivered in a way that meets the needs of this population and that staff are adequately knowledgeable in autism. The importance of asking individuals who use mental health services about their experiences of utilising support is emphasised by NICE (2019), who contend that this feedback should be used to improve services. Additionally, NICE (2016) emphasise the need to ensure that all staff working with autism have an understanding of the following: (1) the nature, development and course of autism, (2) the impact on personal, social, educational and occupational functioning, and (3) the impact of the social and physical environment. The guidance discussed above from NICE coincides with the aims of the current project (see below); this thesis primarily explores the service needs of individuals with co-existing autism and mental health disorder, and also establishes the knowledge of ASD amongst mental health professionals working in adult mental health services.

1.3 Study aims

The current study addresses three aims:

1. To explore the needs and experiences of service users with co-existing autism and mental health disorder,

2. To establish whether the Health Board's adult mental health service meets the needs of service users, and

3. To evaluate knowledge of ASD amongst staff working within adult mental health services in the Health Board.

1.4 Study overview

A mixed methods design was utilised to address the aims of this research project. This research study consisted of two phases, each addressing different aims of the study. Phase 1 involved the undertaking of semi-structured interviews with adults with autism and co-existing mental health disorder, with Phase 2 requiring mental health

professionals to complete an online ASD knowledge questionnaire. A mixed-method design was utilised for this project as using either qualitative or quantitative methods alone would not have been sufficient to address the project aims. This design allowed service users' needs to be determined, and the ASD knowledge of mental health practitioners to be established. The research took place in a health board located in South Wales. Both primary and secondary mental health services were included in the study to provide a broader perspective of services. A more detailed description of the study methodology, design, materials, participants and procedures can be found in chapter five.

1.5 Originality and Contribution to knowledge

At PhD level, research students are required to demonstrate creation and interpretation of new knowledge through original research, with the quality of that work being of a high enough standard to satisfy peer review (University of South Wales, 2019a). The concept of 'originality' requires the student to produce new knowledge that can inform their discipline and current understanding (Gill and Dolan, 2015). In relation to the research questions posed by the current study, at present there is limited existing literature available; this will be evidenced within the literature reviews contained within this thesis. The current study made original contributions to the current knowledge in the following ways: (1) by exploring the mental health service needs of adults with autism accessing services in Wales through the undertaking of semi-structured interviews, (2) by exploring the ASD knowledge of a range of mental health professionals working within a Welsh adult mental health service, and (3) through the development of a novel questionnaire to measure ASD knowledge. However, whilst it is necessary to highlight the original contributions to knowledge of the current thesis, it must be acknowledged that any new knowledge created rests upon on the accumulation of previous and current literature (Dunleavy, 2003), as is the case with the current thesis.

1.6 Reflexivity in research

When carrying out research, it is important to acknowledge that the researcher's values, beliefs and experiences will shape the research being undertaken, and that the research process can in turn shape the beliefs of the researcher. With this recognised, utilising a reflexive approach to research is a way to help improve the

validity of qualitative research. In simple terms, reflexivity can be defined as a process of proactive self-reflection (Shaw, 2010). In practice, reflexivity is the monitoring by a researcher of their impact on the topic under investigation (Gray, 2018). Reflexivity allows the researcher to acknowledge the subtle ways in which bias might affect their research, through their own personal background and beliefs (Gray, 2018).

The concept of reflexivity was discussed by Dupuis (1999) who criticised the concept that to do 'good science' researchers needed to be detached and unemotional. She argued that our interpretations and creations are a reflection of how we see the world, and are dependent on our individual and unique situations (Dupuis, 1999). Dupuis highlighted that the researcher's life experiences affect their study interests, and discussed a concept of two selves (making a full self): the human self and the research self (Dupuis, 1999). The human self being the self we are in everyday situations, and the research self that is created for our specific research situation. It was discussed that the human self influences the research self, and helps to guide the researcher to their research interests. In summary, Dupuis (1999) believed that our two selves cannot be removed from what we do, they can only be omitted.

Dupuis (1999) contends that nothing emerges from the data, instead theories/themes are drawn out of the data by those who collect it. Findings will always be the researcher's interpretations of the participants' interpretations, and Dupuis (1999) stated that the researcher's two selves will influence which issues/themes are highlighted/extracted. Dupuis (1999) discusses strategies to incorporate reflexivity into qualitative research such as researchers explicitly sharing their values, beliefs, interests, motivations, positions and to discuss how they may have influenced various aspects of their research; one proposed strategy is by completing a pre- and post-data collection self-report where changes can be noticed.

Shaw (2010) wrote about embedding reflexivity within qualitative psychology, specifically when employing Interpretative Phenomenological Analysis (IPA). By engaging in reflexivity from the start of our research inquiry, we can use our encounters with participants to help us revise our fore-understandings and come to view the phenomenon anew (Shaw, 2010). Based on the ideas of Dupuis (1999) and Shaw (2010) discussed above, this research will contain a pre- and post-data collection reflexive statement to highlight any differences in the views of the research student

regarding their research topic. In addition to the pre- and post-data collection reflective statements, the researcher kept a reflective diary. The researcher completed diary entries throughout the research process, from the point of seeking ethical approval through to data analysis and writing up the thesis. Please refer to Appendix 1 to see selected entries from the researcher's reflective diary. Shaw (2010) proposed that reflexivity, a way of making explicit our interpretative activities, can be viewed as a way of being/researching that will make researchers' explorations even more successful and illuminating. It is important to note that reflexivity differs from reflection, as reflexivity involves "looking again", and involves the reseacher reflecting their thinking back to themselves (Shaw, 2010, p.234). The researcher engaged in this process during the analysis, repeatedly looking back over diary entries made when analysing participants' transcripts; this process helped to deepen the analysis as the analyst could review her responses to the participants' accounts. The process of reflexivity within the current study allowed the researcher to explicitly examine the relationship between herself and the participants, which in turn informed the analysis.

1.6.1 Researcher Reflexive Statement (Pre-data collection)

I am a white, heterosexual, 24 year old Welsh woman who is physically and mentally well. I am an only child and would consider myself to come from a middle class background, with a very supportive family. I have an undergraduate degree in Psychology with Criminology, and I transitioned straight from this degree to starting my PhD. To make clear my theoretical stance on mental health, I align myself with the biopsychosocial model. This perspective proposes that mental health conditions can be best understood by exploring the interactions between biological, psychological and social factors in an individual's life. In contrast to other models such as the medical model, which focuses solely on biological causes for illness, the biopsychosocial model adopts a holistic approach. I believe it is important to consider individuals as a whole, and to fully understand their experience, as a means to be able to provide appropriate, holistic support. Based on prior education, lived experiences, and information obtained during past and current volunteering, I consider myself to have a reasonable understanding of what autism is. In relation to mental health, my previous studies have introduced me to the literature surrounding a broad range of mental health conditions; however, I have no lived experience of having a mental health condition. Prior to my research study, I had not undertaken any work for the NHS and

therefore knew little about the care pathways within mental health services, and what services were available to people with co-existing autism and mental health disorder. I applied to undertake this funded PhD opportunity as I believed the research topic to be an important one, where I felt there could be potential for real positive change for the participant population. I feel that services, any services, should not be designed and provided without input from the population/community that they are supposed to be serving. My upbringing taught me the value of listening, and the need to avoid jumping to conclusions and/or making assumptions. I feel this research project will allow me to really listen to the experiences (both positive and negative) of adults with autism who have accessed mental health services, and this will provide this population of individuals with the opportunity to feel heard. The media are quick to share horror stories of services, but only through involving service users in research can we paint an accurate picture of services. The need to explore the ASD knowledge of mental health professionals is evident in the literature, and establishing the current knowledge base of staff can help to identify training needs. My hope is that from the findings of this study, recommendations can be made to the health board to improve services for this client group, recommendations that emerge from service user experience.

1.7 Thesis Structure

This chapter started with a brief introduction to the study context, before discussing PhD concepts such as originality and the current study's contribution to knowledge. The chapter then highlighted the importance of reflexivity in research, provided a reflexive statement, and then the structure/content of this thesis was outlined. The remaining content of this thesis will follow the below structure:

Chapter two will set the wider context for the study, offering a detailed description of autism, then moving on to discuss co-existing mental health disorder(s) in autism. An overview of mental health services will then be presented, with relevant legislation and guidance discussed.

The third chapter examines the existing literature exploring the lived experiences of individuals who have autism in relation to accessing healthcare services.

The fourth chapter explores the existing literature in relation to healthcare professionals' knowledge of ASD, before the rationale for the current study is provided.

Chapter five will provide details of the research design, methodology, participant recruitment criteria, data collection methods, research procedure and analysis process that was used in this study, as well as ethical considerations.

Chapter six will provide the results obtained from Phase 1 (service users) of the research study, whereby semi-structured interviews and IPA were utilised to explore study aims one and two.

Chapter seven will contain the findings of Phase 2 (mental health professionals) addressing study aim three which used an online questionnaire to measure mental health professionals' knowledge of ASD.

Chapter eight is the discussion chapter which will bring together the findings of both of the phases, whilst linking the findings to existing literature and clinical guidance. The limitations of the current study will also be highlighted.

The final chapter, chapter nine, will specifically address the research questions of the current study, and will discuss the implications of the research findings. Recommendations for practice, and recommendations for future research will be highlighted before the researcher's post-data collection reflexive statement is provided to conclude.

Chapter Two: Context

"*If you've met one person with autism, you've met one person with autism*."

- Dr. Stephen Shore (The Art of Autism, 2020, para.2)

2.1 Introduction

This chapter will firstly discuss autism before moving on to examine the co-existence of mental health disorders in autism. A brief overview of mental health services will also be provided, with relevant legislation and guidance then being discussed.

2.2 Autism

The term autism started appearing in the literature in the 1900s. Almost concurrently, Leo Kanner and Hans Asperger published works about an autistic presentation in children (Chaplin, Spain and McCarthy, 2020). In their works, both Kanner and Asperger reported comparable impairments in social interaction and relatedness, poor understanding of others, atypical communication, and the presence of set repetitive behaviours in their samples (Chaplin, Spain and McCarthy, 2020). The differences in their works were that Kanner indicated the autistic presentation to be associated with developmental delay and intellectual disability, whereas Asperger stated he found the presentation to correspond with average intelligence (Chaplin, Spain and McCarthy, 2020). A diagnosis of infantile autism (described as a pervasive developmental disorder) was first introduced in the third edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-3; American Psychiatric Association, 1980). Over time the label and diagnostic criteria of autism has changed, with Autism Spectrum Disorder (ASD) being the current term contained within both the 5th edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5; American Psychiatric Association, 2013) and the 11th edition of the International Classification of Diseases (ICD-11, World Health Organisation, 2019b). However, the DSM-5 highlights that previous diagnoses such as early infantile autism, childhood autism, Kanner's autism, high-functioning autism, atypical autism, pervasive developmental disorder not otherwise specified, childhood disintegrative disorder and Asperger's disorder would now be encompassed under the current classification of ASD (APA, 2013).

Based on current understanding, ASD is a neurodevelopmental disorder, which is a condition that manifests in childhood and affects individuals throughout their lifespan (APA, 2013). ASD affects an individual's social communication, interactions, behaviours, interests, and activities, with a prevalence of approximately 1% of the population (APA, 2013). Based on a prevalence rate of 1% and the population of Wales being 3,205,362 in 2019 (UK Population, 2020), it is estimated that approximately 32,054 people in Wales may have ASD. Over the past 50 years, the prevalence of ASD has increased globally (WHO, 2019c). WHO (2019c) stated that potential explanations for this increasing prevalence could be the expansion of the diagnostic criteria, improved awareness, better diagnostic tools and improved reporting. However, Fletcher-Watson and Happé (2019) state that interpreting changes in autism prevalence over time is very challenging due to changing diagnostic criteria and potential differences in how professionals apply the diagnostic criteria in different settings.

Both diagnostic manuals (DSM-5 and ICD-11) group ASD characteristics into two categories (known as a dyad of impairments); the first category includes difficulties with communication, social interaction and relatedness, and the second category encompasses restricted and repetitive behaviours, as well as stereotyped speech (Chaplin, Spain and McCarthy, 2020). However, the DSM-5 and ICD-11 have variations in the wordings used regarding the two categories. According to the DSM-5, to obtain a diagnosis an individual would have to show "persistent deficits in social communication and social interaction across multiple contexts" and have "restricted, repetitive patterns of behavior, interests or activities" (APA, 2013, p.50). See the below table (Table 1) providing the detailed DSM-5 diagnostic criteria for ASD. The DSM-5 also highlights that individuals with ASD will probably have sensory differences such as hyper- or hypo-reactivity to sensory input (APA, 2013).

Table 1: DSM-5 Diagnostic Criteria for ASD

Diagnostic criteria	**Manifestation**
Persistent deficits in social communication and interaction	All of the following required: ▪ Deficits in social emotional reciprocity ▪ Deficits in nonverbal communication behaviours used for social interaction ▪ Deficits in developing, maintaining, and understanding relationships
Restricted, repetitive patterns of behaviour, interests, or activities	At least two of the following required: ▪ Stereotyped/repetitive movements, use of objects, or speech ▪ Insistence on sameness, inflexible adherence to routines, or ritualised forms of verbal/non-verbal behaviour ▪ Restricted, fixated interests that are atypical in intensity or focus ▪ Hyper-reactivity or hypo-reactivity to sensory stimulus or atypical interest in sensory aspects of their surroundings

Source: Adapted from the DSM-5 (APA, 2013)

The ICD-11 wording differs slightly stating that people with ASD have persistent deficits in their ability to initiate and sustain reciprocal social interactions and social communication, and also have restricted, repetitive and inflexible patterns of behaviours and interests (WHO, 2019b). For a diagnosis of ASD, the features of ASD mentioned above, in both diagnostic manuals, must have been present from an individual's childhood; but both the DSM-5 and ICD-11 acknowledges that ASD characteristics may only fully manifest later when social demands exceed an individual's capacities (APA, 2013; WHO, 2019b). This is discussed by Chaplin, Spain and McCarthy (2020) who propose that characteristics may seem subtler when an individual is younger and may become more apparent or severe with age, and/or that

characteristics may become more prominent in less structured situations. It is also important to acknowledge that many individuals with ASD will also have language impairment and/or intellectual impairment (APA, 2013) with approximately 45% of individuals with ASD also having intellectual disability (Lai, Lombardo and Baron-Cohen, 2014). Additionally, it is very common for neurodevelopmental disorders to co-occur; therefore, it is very likely that an individual with ASD may have another developmental disorder. The DSM-5 states that Specific Learning Difficulties (literacy and numeracy) and Developmental Coordination Disorder (DCD) is common alongside ASD (APA, 2013). The co-occurrence of ASD with other neurodevelopmental disorders is supported by Hofvander et al. (2009) who found that 43% of their sample of adults with ASD were also diagnosed with Attention Deficit Hyperactivity Disorder (ADHD), and Cassidy et al. (2016) found adults with autism were significantly more likely to report a diagnosis of DCD (6.9%) than adults without autism (0.8%). In addition to co-occurring neurodevelopmental disorders, some individuals with ASD may have Alexithymia, which is when individuals have difficulties identifying and describing their own feelings and emotions (Chaplin, Spain and McCarthy, 2020). Much higher rates of Alexithymia are seen in individuals with ASD (40-65%) compared to the general population (approximately 10%) (Bird and Cook, 2013). Professionals supporting individuals with ASD need to be aware of the possible co-existence of other neurodevelopmental disorders and Alexithymia with ASD to enable them to offer holistic support to this population.

For a diagnosis of ASD to be given, an individual's difficulties must cause significant impairment to the individual in either social, occupational or other important areas of daily functioning (DSM-5; APA, 2013). The ICD-11's wording is that the deficits must be sufficiently severe to cause impairment; examples of areas where functioning may be affected include personal, family, social, education and occupation functioning (WHO, 2019b). The ICD-11 acknowledges that people with ASD exhibit a range of intellectual functioning and language abilities (WHO, 2019b). The word spectrum in ASD illustrates that there is considerable variation in the severity and type of characteristics that people with ASD experience. There is significant inter-individual variation in the features that result in a diagnosis of autism, but the shared behaviours associated with autism, and emotional and/or sensory differences, have resulted in the collective diagnostic term of Autism Spectrum Disorder (Purkis, Goodall and

Nugent, 2016). The National Institute for Health and Care Excellence (NICE, 2014) discuss the clinical picture of ASD, and state that it is variable due to differences in the severity of ASD, the presence of co-existing conditions and the differing levels of intellectual ability. Three levels of ASD severity are detailed in the DSM-5: requiring support (Level 1), requiring substantial support (Level 2) and requiring very substantial support (Level 3) (APA, 2013). Professionals are required to assign a severity level for both of the ASD symptom categories, and detail the level of support required (Chaplin, Spain and McCarthy, 2020). It is important to note here that the terminology of 'severity' reflects a medical model approach to viewing autism. However, as we will see later in this chapter, there are alternatives to this model.

In relation to ASD diagnoses, a gender difference is prevalent with research showing a greater number of males with ASD than females. A meta-analysis conducted by Loomes, Hull and Mandy (2017) found the male-to-female ratio in ASD to be close to 3:1. They argued that there appears to be a diagnostic gender bias whereby girls who meet the criteria for a diagnosis of ASD are at a larger risk of not receiving a diagnosis compared to boys (Loomes, Hull and Mandy, 2017). Furthermore, Moseley, Hitchiner and Kirkby (2018) contend that there is an inherent bias to the diagnosis of autism as diagnostic tools and screening instruments for ASD are undeniably androcentric, as they were developed and standardised according to the presentation of ASD in males. Relatedly, the DSM-5 notes that some individuals may mask their symptoms by utilising learned strategies in later life (APA, 2013). Masking, along with compensation, are considered the two core components of camouflaging (Hull et al., 2019). Camouflaging is when an individual with autism conceals their social communication difficulties from others, but this does come at a cost to the individual as it requires considerable cognitive effort (Lai et al., 2017). It has been suggested that camouflaging may be a potential explanation as to why fewer women are diagnosed with ASD compared to men, with higher camouflaging scores found in women with autism than men with autism (Lai et al., 2017). In their study exploring the camouflaging experiences of adults with ASD, Hull et al. (2017) proposed that camouflaging should not necessarily be considered a beneficial behaviour, and additionally should not be encouraged for people with autism as camouflaging may increase mental health difficulties in this population. One explanation provided for presence of masking in individuals with autism is the experiencing of stigma (Pearson

and Rose, 2021). It is proposed that due to autism being perceived in society as an impairment, autism is given pathologised status which leads to stigma, dehumanisation and marginalisation of individuals with autism (Pearson and Rose, 2021). Pearson and Rose (2021) contend that stigmatised individuals, such as those with autism, may attempt to hide aspects of their identity from others in an attempt to be perceived as normal. It was highlighted by Hull et al. (2017) that camouflaging could result in a delay or questioning of an individual's ASD diagnosis due to the presentation being less obvious; this was especially found to be the case when the individual was female (Hull et al., 2017). Varying potential explanations for the gender differences seen within camouflaging were proposed by Hull et al. (2017) such as differences in the actual camouflaging techniques that individuals of different genders use, or that females with ASD who camouflage tend to do so more successfully than males.

In relation to the diagnosing of ASD, it is stated that diagnoses have higher validity and reliability when they are based on multiples sources of information which includes observations by the professional, a detailed history from the caregiver, and if possible, self-reported information from the individual being assessed (APA, 2013). Building on this, NICE (2016) guidelines for Autism Spectrum Disorder in adults state that diagnosis should: be undertaken by trained and competent professionals, be team-based involving a variety of professionals, and should where possible include a family member, partner, carer or informant as well as documentary evidence. However, it is important to note that a diagnosis is only useful when it is beneficial to the person ; for example, if the diagnosis allows the individual to access support (Purkis, Goodall and Nugent, 2016).

The manifestation of atypical development and corresponding behaviours is a multifaceted interplay between genetic vulnerabilities and environmental influences (Purkis, Goodall and Nugent, 2016). However, the above discussion highlights that ASD is currently assessed and diagnosed on the basis of behaviour. Although it is known that autism has genetic contributions, no reliable biological marker has been identified which could assist with an autism diagnosis and therefore ASD is currently identified based on a set of behaviours (Fletcher-Watson and Happé, 2019). Fletcher-Watson and Happé (2019) argue that a reliance on using behaviour to diagnose autism leads to challenges for professionals in the field. For instance, clinicians need to be aware that the same feature could appear differently across different people; for

example, for one person social communication difficulties could mean that an individual is selective mute or for another it could mean the individual speaks fluently but has difficulty understanding non-literal language (Fletcher-Watson and Happé, 2019). Fletcher-Watson and Happé (2019) state that loosely defined criteria can present challenges to differential diagnosis, risks mis-diagnosis, and can lead to difficulty when a support package has to be matched to the diagnosis. However, the idea that intervention needs to be matched to a diagnosis is debatable, with person-centred approaches contending that the focus should be on helping individuals to become fully functioning, without a need to rely on psychiatric labels (Joseph, 2017).

A lot of the information discussed in this chapter so far aligns with the medical model of disability; the medical model focuses on the impairments that an individual possesses and attempts to rectify them (Beardon, 2017). This focus is due to the fact that the current research project was undertaken in collaboration with a local health board, with health boards operating largely within the medical model (Welsh Government, 2019) and being heavily reliant on diagnoses. Through the medical model lens, autism is viewed as a deficit and something that needs to be fixed/changed (Beardon, 2017). An alternative model of disability is the social model; this model rejects a deficit-focused understanding (Anderson-Chavarria, 2021) and instead contends that it is society which disables impaired people (Union of the Physically Impaired Against Segregation [UPIAS], 1976). The social model emphasises the difference between 'impairment' and 'disability' (Booth, 2016). The UPIAS (1976) stated that within the social model, disability can be viewed as a disadvantage or restriction placed on people with impairment(s) due to way that society is organised (UPIAS, 1976). Disability is imposed on people in addition to any impairment(s) experienced by the way in which society unnecessarily isolates and excludes individuals, therefore, not allowing them to fully participate in society (UPIAS, 1976). The social model looks beyond the biological unlike the medical model, and explores the political, economic and socio-interactional context of the person with disability (Anderson-Chavarria, 2021). In relation to autism, both of the above models have faced criticism; the medical model is criticised for possessing a purely deficit-based view of autism as where the social model has been criticised for being overly reliant on the critique of systems (Anderson-Chavarria, 2021), and for also failing to acknowledge the role impairment plays in relation to disability (Shakespeare, 2006).

Shakespeare (2006) offered a differing approach to disability, proposing disability to be an interaction between factors intrinsic to the individual and extrinsic factors. Instead of fixating on either the medical model or social model as an explanation for disability, Shakespeare (2006) proposed a need for a more holistic understanding.

An alternative model of disability through which to view autism is the predicament model. This model, akin to the thinking of Shakespeare (2006), aims to understand disability more holistically. The predicament model understands disability to be both biologically based and socially constructed, whereby individuals with atypical functionality are often restricted in a society not developed with atypicality in mind (Anderson-Chavarria, 2021). When applied to autism, this model can encompass the real difficulties that individuals with autism can experience due to their condition (for example, painful sensory experiences) but can also appreciate the disabling impact that a primarily neurotypical society can have on the individual. A disjointedness between individuals with autism and neurotypical individuals was raised by Milton (2012) in his work discussing the "double empathy problem" (p.884). The double empathy problem contends that communication is a two-way street; so whilst it is true that individuals with autism may often lack insight about neurotypical perceptions and culture, it is also true that neurotypical individuals lack insight into the minds and culture of individuals with autism. So whilst autism may cause differences in sociality due to differences in neurology, it may be incorrect to state that autism is a social deficit as communication is an interaction with two or more responsible parties (Milton, 2012). The concept that communication difficulties arise from a mismatch in neurotype is supported by Crompton et al. (2020) who found individuals with autism were able to effectively share information with each other, with information being shared less effectively in a mixed sample of both neurotypical individuals and individuals with autism. This finding challenges the idea that individuals with autism lack the skills to interact and communicate successfully (Crompton et al., 2020).

2.3 Mental health difficulties in autism

The DSM-5 highlights that many individuals with ASD have additional psychiatric symptoms that do not form part of the diagnostic criteria for ASD (APA, 2013). It is stated that about 70% of individuals with ASD have one co-existing mental health disorder, with around 40% having two or more co-existing mental health disorders

(APA, 2013). Existing literature supports the concept of high comorbidity between autism and mental health difficulties. For example, research conducted by Simonoff et al. (2008) involving 112 children with ASD demonstrated that 70% of their sample had at least one co-existing psychiatric disorder, with 41% having two or more. Likewise, Lever and Geurts (2016) explored this issue in an adult sample consisting of 247 adults with ASD, aged 19 to 79 years, and found that 79% of the sample met the criteria for a psychiatric disorder at least once in their lives. Within this percentage, 20.3% had one lifetime psychiatric diagnosis, 13.8% had two, 17.4% had three, 12.3% had four and 15.2% had more than four psychiatric diagnoses in their lifetime (Lever and Geurts, 2016). Lai, Lombardo and Baron-Cohen (2014) contend that it is generally the case that the more co-existing conditions an individual has, the greater their impairment. Furthermore, research by Croen et al. (2015) demonstrated that adults with ASD have significantly increased rates of many psychiatric disorders including bipolar disorder, obsessive-compulsive disorder, schizophrenia, and suicide attempts compared to a control group of individuals without ASD. The relationship between autism and mental illness is also supported by Tromans et al. (2018) who found the prevalence of ASD to be increased in inpatient psychiatric settings compared to the general population.

The findings of Lever and Geurts (2016) suggests that almost 4 in 5 adults with autism will experience a co-existing psychiatric disorder at least once in their lifetime. In the general population, it is believed that one in four adults experience mental health difficulties (Welsh Government, 2012). This illustrates how adults with autism are much more likely than the general population to experience mental health difficulties. Research by Russell et al. (2016) investigating the mental health of individuals with autism found high rates of co-existing psychiatric diagnoses in people with autism and highlighted the need for careful consideration of the mental health needs of this population. The above studies illustrate that many, if not most, individuals with autism will experience co-existing mental health difficulties, and may require support from mental health services. Additionally, it is highlighted by Munesue (2008) that ASD (specifically high-functioning ASD) is sometimes unrecognised and undiagnosed in individuals who seek care for other psychological difficulties, illustrating that staff may not be fully aware of the co-existence of autism and mental health difficulties. This may indicate that mental health professionals could benefit from autism training. This

chapter will now go onto explore the co-existence of autism with the following eight mental health conditions individually: anxiety, depression, bipolar disorder, obsessive compulsive disorder, post-traumatic stress disorder, personality disorder, gender dysphoria and alcohol dependency. These eight disorders are discussed specifically as they were the current co-existing mental health disorders reported by the participants in this study. Self-harm, suicidal ideation and suicidal behaviour in autism will also be discussed as these were topics highlighted within the service user interviews.

2.3.1 Autism and Anxiety

Everyone experiences anxiety; it is normal to have anxiety at certain times. However, anxiety can also become overwhelming and damaging (Purkis, Goodall and Nugent, 2016) with some individuals experiencing clinical levels of anxiety. Some people experience severe anxiety feeling anxious for much or all of the time, and the majority of people with autism may fall into this category (Purkis, Goodall and Nugent, 2016). Anxiety can either be related to specific things, or more generalised. The DSM-5 describes anxiety disorders as disorders that share features of excessive fear and anxiety and associated behavioural disturbances (APA, 2013). Anxiety disorders differ in the types of objects or situations that result in fear, anxiety or avoidance behaviour, and the associated thoughts and beliefs (APA, 2013). When looking at the co-existence of clinical anxiety in autism, Lai, Lombardo and Baron-Cohen (2014) reported that 42-56% of individuals with autism had anxiety disorders, stating that social anxiety disorder and generalised anxiety disorder were the most common anxiety disorders in their sample. A comparable rate was reported by Cai et al. (2018) who found that 42.6% of their sample reached the criterion for clinical levels of anxiety.

Social anxiety disorder (also known as social phobia) is when an individual experiences fear or anxiety about, or is avoidant of, social situations and interactions that could potentially involve the individual being scrutinised (APA, 2013). Examples of situations include meeting new people, situations which may involve the person being observed whilst eating/drinking, and situations where the person may have to perform in front of other people (APA, 2013). The thoughts and feelings associated with social anxiety disorder revolve around being viewed negatively by others, embarrassment, rejection, humiliation or offending others (APA, 2013). Bejerot,

Eriksson and Mörtberg (2014) examined social anxiety in individuals with ASD who had average or above intelligence and found that 28% of individuals in their sample also fulfilled the diagnostic criteria for social anxiety disorder. The DSM-5 provided a mean prevalence of 2.3% for social anxiety disorder in Europe (APA, 2013); this again illustrates the higher risk of mental health difficulties in people with autism. In fact, the DSM-5 suggests ASD as a differential diagnosis to social anxiety disorder, stating that social anxiety as well as social communication difficulties are hallmarks of ASD (APA, 2013). This idea is discussed by Purkis, Goodall and Nugent (2016) who contend that it is not absolutely clear whether anxiety is an innate part of autism, or if anxiety is a co-existing phenomenon.

The other most common form of anxiety disorder mentioned by Lai, Lombardo and Baron-Cohen (2014) was Generalised Anxiety Disorder (GAD). According to the DSM-5, GAD involves an excessive and persistent anxiety and worry in various domains that the individuals finds challenging to control, such as school/work performance (APA, 2013). Physical symptoms associated with generalised anxiety disorder include restlessness, feeling on edge, fatigue, difficulty concentrating, irritability, muscular tension and sleep disturbances (APA, 2013). In a study undertaken by Joshi et al. (2013), it was found that 22 of the 63 (35%) adults with ASD in their sample had or have had a diagnosis of generalised anxiety disorder at some point in their life.

Chaplin, Spain and McCarthy (2020) provide suggestions as to why anxiety is so common in individuals with autism. They discuss the following four concepts: intolerance of uncertainty, alexithymia, information processing and emotional dysregulation (Chaplin, Spain and McCarthy, 2020). Intolerance of uncertainty can be considered a negative response to uncertain situations, and this can result from a need for predictability and an individual finding it difficult to deal with uncertainty (Chaplin, Spain and McCarthy, 2020). Alexithymia, discussed previously, is when an individual has difficulties identifying and describing their own feelings and emotions (Chaplin, Spain and McCarthy, 2020). Higher rates of Alexithymia are seen in people with autism, and this could play a role in the higher prevalence of anxiety disorders seen in the population. Additionally, individuals with autism are known to experience difficulties with processing information. Chaplin, Spain and McCarthy (2020) propose that these difficulties can cause social and functional challenges, which can cause difficult interactions with others, which can trigger negative beliefs, which can then result in

feelings of stress and anxiety. The last mechanism discussed by Chaplin, Spain and McCarthy (2020) is emotional dysregulation, and they argue poor emotion regulation may be expressed/interpreted as anxiety.

Purkis, Goodall and Nugent (2016) propose that some people with autism do not realise they have severe anxiety as they either have not noticed or have not identified the symptoms they are experiencing as anxiety. Rodgers et al. (2012) undertook research to explore the relationship between anxiety and repetitive behaviours in autism. They found higher levels of restricted and repetitive behaviours, insistence on sameness/circumscribed interests and sensory-motor behaviours in children with ASD and anxiety, compared to children with ASD allocated to a non-anxious group (Rodgers et al., 2012). Rodgers et al. (2012) argued that anxiety may be a strong motivator for the repetitive behaviours seen in people with autism, and suggest that repetitive behaviours may be a maladaptive coping response (Rodgers et al., 2012). However, individuals with autism have reported that stimming (another term used for repetitive behaviours) can be calming and enable them to make more sense of their thoughts (Vivian, 2012) and also serve a self-regulatory function (Kapp et al., 2019), Therefore, repetitive behaviours may not be a maladaptive coping strategy but instead an effective means of regulating emotions. However, due to societal stigma, some individuals with autism reported that they attempt to suppress their stims, but this comes with depleting and effortful costs (Kapp et al., 2019) which could have a negative impact on an individual's mental health. Whilst acknowledging that stimming may be used to reduce an individual's anxiety, the National Autistic Society (2020) states that there can be other reasons for repetitive behaviours, such as the behaviours being a means of gaining or reducing sensory input, as well as the individual enjoying the repetitive behaviour. The importance of individuals being able to recognise and understand their anxiety is emphasised by Purkis, Goodall and Nugent (2016), as the recognition of anxiety allows the individual to be able to work towards decreasing and managing their anxiety.

2.3.2 Autism and Depression

Depression is another mental health condition commonly seen in individuals with autism. According to Purkis, Goodall and Nugent (2016) variations in mood is part of being human, but when the dips in mood become too low, or negative emotions are

dominant, depression may be the explanation. Although depression is considered a disorder of the mind, it is important to note that depression is also commonly associated with physical symptoms such as fluctuations in weight and/or insomnia or somnolence (Purkis, Goodall and Nugent, 2016). The DSM-5 contains a group of conditions called depressive disorders (APA, 2013). The common feature of all the disorders within this group is that they require the presence of sad, empty or irritable mood, accompanied by cognitive and physical changes that significantly impair an individual's ability to function (APA, 2013). The differences between the disorders are to do with the duration, timing or presumed causes of the disorder (APA, 2013).

Major Depressive Disorder (MDD) is a condition contained within the DSM-5 which represents the "classic condition" of depression (APA, 2013, p.155). MDD is characterised by separate episodes of at least 2 weeks' duration where differences in the individual's function has been seen such as changes in affect, cognition, neurovegetative functions (e.g. sleep disturbance, fatigue, change in appetite) and inter-episode remissions (APA, 2013). A diagnosis of MDD can be given for a single episode, but the disorder is recurrent in the majority of cases (APA, 2013). A more chronic form of depression, Persistent Depressive Disorder (PDD; also known as Dysthymia), can be diagnosed when the mood disturbance continues for at least 2 years in adults, or 1 year in children (APA, 2013).

In their seminar paper about autism, Lai, Lombardo and Baron-Cohen (2014) proposed a 12-70% co-existence between ASD and depression. Lai, Lombardo and Baron-Cohen (2014) state that depression is less common in children, and more common in adults, with high-functioning adults who are less socially impaired being more susceptible, or the symptoms being more obvious. A study conducted by Lugnegård, Hallerbäck and Gillberg (2011) looked at psychiatric comorbidity in a sample of young adults with Asperger syndrome and found that 70% had experienced at least one episode of major depression, with 50% having suffered from recurrent depressive episodes. Lever and Geurts (2016) reported lifetime rates of co-existence in their sample of adults with ASD, and found that 53.6% and 18.1% had experienced depression and dysthymia respectively, as where a lower rate was found by Russell et al. (2016) who reported that 15.8% of their ASD sample had experienced a depressive episode.

Potential factors that may precipitate or excerbate depression in people with autism include: an awareness of being different and not fitting in, trauma, bullying, the process of obtaining an autism diagnosis, loneliness/isolation, grief/loss, feelings of failure, high levels of anxiety and/or having a genetic predisposition (Purkis, Goodall and Nugent, 2016). Chaplin, Spain and McCarthy (2020) also discuss factors that may account for depression in autism, and they propose: negative life events, intellectual level and exhibiting higher cognitive abilities, being less socially impaired, multiple psychiatric morbidities and parental distress. Research by Cai et al. (2018) found both intolerance of uncertainty and emotional regulation to be mediating factors in their study examining depression in ASD, with 36.1% of their sample meeting the diagnostic criteria for depression. When considering the above mentioned factors, it is important to distinguish between issues related to an individual's impairment (such as genetic predisposition and intellectual level) and issues arising from within society (such as bullying). Additionally worth noting, factors intrinsic to the individual and external factors can interact which can further impact on the individual. However, Purkis, Goodall and Nugent (2016) highlight that depression sometimes goes unnoticed or misdiagnosed in people with autism as depression can present differently in this population. They argue that many individuals are incorrectly diagnosed with psychotic disorders, schizophrenia or personality disorders (Purkis, Goodall and Nugent, 2016). It is argued that one reason that depression is missed in people with autism is because they are not able to express their emotions as clearly/visibly as neurotypical people can; people with autism may appear to have a mood which is always flat, whether experiencing depression or not (Purkis, Goodall and Nugent, 2016).

2.3.3 Autism and Bipolar Disorder

Bipolar Disorder, also known as Bipolar Affective Disorder, is a mental health condition that affects an individual's mood. Everyone experiences variations in their mood, but for people with bipolar their high and low moods are extreme, and the mood swings they experience are overwhelming (Mind, 2018). The word bipolar symbolises the way an individual's mood can change between mania (or hypomania) and depression (Mind, 2018). Mania and hypomania are episodes of over-active or excited behaviour that impact significantly on an individual's day-to-day functioning (Mind, 2020). Mania is more severe than hypomania, having a serious negative impact on an individual's day-to-day functioning, lasting for a longer period (a week of more). Hypomania is less

severe, lasts for a shorter period (typically a few days) and can feel more manageable to the individual, but it can still be disruptive and the change in the individual's mood/behaviour may be observable by others (Mind, 2020). According to the DSM-5, a major depressive episode must last for at least 2 weeks with the individual either displaying depressed mood or a loss of interest/pleasure (APA, 2013). Mind (2018) suggest that the depressive episodes can feel harder for the individual to deal with compared to the manic/hypomanic episodes as the contrast between high and low mood can make the depression feel even deeper.

Bipolar I and Bipolar II are detailed within the DSM-5 (APA, 2013). A diagnosis of Bipolar I necessitates an individual having at least one episode of mania which lasted for longer than a week; however, the DSM-5 also highlights that the individual may have experienced hypomanic or major depressive episodes prior to or following the manic episode (APA, 2013). For a diagnosis of Bipolar II, an individual must have experienced a current or past hypomanic episode, as well as having had a current or past major depressive episode (APA, 2013). Alternatively, a diagnosis of Cyclothymic Disorder can be given to adults who experience both hypomanic and depressive periods for 2 years, without needing to satisfy the criteria for an episode of mania, hypomania, or major depression (APA, 2013).

The Adult Psychiatric Morbidity Survey was carried out in 2014 and found that 2% of participants screened positive for bipolar; based on this they estimated the rate of bipolar in the wider population to be somewhere between 1.6% and 2.4% (McManus et al., 2016). According to Chaplin, Spain and McCarthy (2020), the range for someone with autism being diagnosed with bipolar disorder is 1% to 15%. In a sample of 122 adults with ASD with average or above intelligence, Hofvander et al. (2009) found that 10 (8%) met the criteria for a bipolar disorder with five having Bipolar I, two having Bipolar II and three being coded as unknown subtypes. In contrast, Joshi et al. (2013) found that 25% of their sample of adults with autism had at some point in their lives received a diagnosis of Bipolar I. Munesue (2008) also found a higher prevalence of co-existing bipolar disorder with 12 out of their 44 outpatient participants with autism (27%) having a bipolar disorder, with two patients having Bipolar I, six having Bipolar II and four having Bipolar disorder not otherwise specified. However, a systematic literature review to explore the co-existence between ASD and bipolar disorder was undertaken by Skokauskas and Frodl (2015) and they concluded that 7% of the overall

sample of people with ASD had Bipolar disorder, compared to the 2% found in the general population by McManus et al. (2016). This indicates that people with ASD are approximately 3 times more likely to experience Bipolar compared to the general population. However, it must be acknowledged that Bipolar Disorder and ASD are fairly heterogeneous conditions, which can contribute to nosological complexities (Skokauskas and Frodl, 2015) and potentially result in elevated rates of co-existence.

Based on the co-existence of ASD and Bipolar Disorder, Munesue (2008) proposed that ASD might share common vulnerability genes with Bipolar Disorders. This concept of shared genetic factors is supported by the Cross-Disorder Group of the Psychiatric Genomics Consortium (2013) who identified specific variants in calcium channel activity genes that were shared between ASD, ADHD, Major Depressive Disorder, Bipolar Disorder and Schizophrenia. Skokauskas and Frodl (2015) stressed the importance of accurate detection of Bipolar Disorder in ASD in order for individuals to receive more targeted treatment to improve the individual's functioning and quality of life (Skokauskas and Frodl, 2015). They argued that co-existing Bipolar Disorder may severely impair people who already have limited cognitive functioning and social skills (such as some people with autism) and this may lead to further psychological/psychosocial impairment and higher hospitalisation rates (Skokauskas and Frodl, 2015).

2.3.4 Autism and Obsessive Compulsive Disorder

Obsessive Compulsive Disorder (OCD) is characterised by an individual experiencing obsessions and/or compulsions (APA, 2013). According to the DSM-5 obsessions are intrusive and unwanted persistent recurring thoughts, urges, or images, whereas compulsions are repetitive behaviours or mental acts that an individual feels they have to perform in response to an obsession (APA, 2013). For a diagnosis of OCD to be given, the obsessions and/or compulsions must be time consuming to the individual (more than one hour a day) or cause significant distress or impairment to the individual's functioning (APA, 2013). When giving a diagnosis of OCD, the professional needs to specify what level of awareness the individual has in relation to their OCD beliefs (APA, 2013). For this there are three categories: with good or fair insight (recognition that the OCD beliefs are definitely or probably not true), with poor insight (the individuals believes the OCD beliefs are probably true) or with absent

insight/delusional beliefs (the individual believes the OCD beliefs to be true) (APA, 2013). The DSM-5 proposed that the prevalence of OCD internationally is between 1.1% to 1.8% (APA, 2013); this is supported by McManus et al. (2016) who found OCD prevalence to be 1.3% in the general population in their 2014 Adult Psychiatric Morbidity Survey in England.

However, OCD is found to be more prevalent in people with autism. Hofvander et al. (2009) explored lifetime rates of mental health disorders in adults with ASD and found that 24% of adults with autism also had OCD. This high prevalence was also found by Lever and Geurts (2016) who also examined lifetime rates of mental health difficulties and found that 21.7% of adults with ASD had OCD compared to 0.6% in a comparison group of adults without ASD. However, Lugnegård, Hallerbäck and Gillberg (2011) state that OCD as a co-existing diagnosis to ASD is controversial given that rituals and rigid adherence to routines is common in ASD. They found only 7% of adults with Asperger's syndrome had co-existing OCD (Lugnegård, Hallerbäck and Gillberg, 2011). In their study, only participants that were distressed by their compulsive rituals and/or obsessive thoughts were given a co-existing diagnosis of OCD, and this along with differences in study populations could account for the difference in prevalence found (Lugnegård, Hallerbäck and Gillberg, 2011). Although the prevalence rates of OCD in individuals with ASD differ, the prevalence of OCD in this population is clearly higher than in the general population. The relationship between ASD and OCD has been further supported by Wikramanayake et al. (2018) who found that 27.8% of the adult OCD outpatients in their sample met the diagnostic criteria for previously undiagnosed ASD. Although, it could be argued that ASD compulsions are being mis-diagnosed as OCD, and this could explain why some individuals diagnosed with 'OCD' might fail to respond to the standard treatments offered for OCD (Wikramanayake et al., 2018).

Galanopoulos et al. (2014) argued that OCD in people with autism may be overlooked as it could be mistaken for repetitive behaviour seen in autism. However, they emphasise the difference between repetitive behaviour and OCD. Rosen et al. (2018) stress the importance of evaluating whether obsessions are distressing and intrusive to the person, and if repetitive behaviours are compulsive or rather a preoccupation arising from ASD symptoms that the individual enjoys. Galanopoulos et al. (2014) propose that although there is increasing awareness of OCD in this population, it is

still under-recognised and therefore many people are not receiving the appropriate treatment. Meier et al. (2015) argue the high co-existence, sequential risk and shared familial risks between OCD and ASD indicate common contributory mechanisms between the conditions. They mention both genetic and environmental risk factors as playing a role in the development of OCD and ASD (Meier et al., 2015).

2.3.5 Autism and Post-Traumatic Stress Disorder

Post-Traumatic Stress Disorder (PTSD) is considered a "trauma- and stressor- related disorder" within the DSM-5 (APA, 2013, p.265). The essential component of PTSD is the development of characteristic symptoms after experiencing at least one traumatic event (APA, 2013). Examples of these symptoms include: presence of intrusion symptoms, persistent avoidance of stimuli associated with the event, negative changes in mood and thoughts, and marked changes in arousal and reactivity (APA, 2013). An individual may re-experience the traumatic event in a number of ways, e.g. involuntary, recurring and intrusive recollections, or distressing dreams related to the event (APA, 2013). Additionally individuals with PTSD will persistently avoid both internal (e.g. thoughts, feelings and memories) and external (e.g. people, places, situations, objects) stimuli related to the event (APA, 2013). The duration of the above mentioned symptoms needs to exceed one month and be significantly distressing or impairing to the individual for a diagnosis to be given (APA, 2013). Gender differences are seen in PTSD with more frequent diagnosis in females compared to males across the lifespan, with females also experiencing PTSD for longer periods of time than males (APA, 2013).

In regard to prevalence of PTSD in the general population, the Adult Psychiatric Morbidity Survey undertaken in 2014 found that 4.4% of their participants had screened positive for PTSD in the past month (McManus et al., 2016). When looking at individuals with autism, Chaplin, Spain and McCarthy (2020) highlighted that there is very limited evidence available regarding the prevalence of PTSD in this population. In a study exploring the experience of trauma and PTSD symptoms in adults with ASD, Rumball, Happé and Grey (2020) found that 40% of their sample of adults with autism showed probable PTSD within the last month, and over 60% reporting probable PTSD at some point in their lifetime. This indicates that individuals with autism might be at increased risk of developing PTSD following exposure to a traumatic event. Kerns,

Newschaffer and Berkowitz (2015) debated possible reasons for this increased risk of PTSD in individuals with ASD. They discussed socio-cognitive features of ASD such as impairments in theory of mind, difficulties with executive functioning, impaired emotional insight and mental rigidity as potentially diminishing the use of coping strategies leading to an exaggerated trauma response (Kerns, Newschaffer and Berkowitz, 2015). It has been suggested that people with ASD may lack the social interest, skill or network to feel understood, and therefore be supported, by others when dealing with trauma (Kerns, Newschaffer and Berkowitz, 2015). Kerns, Newschaffer and Berkowitz (2015) also highlight that individuals with ASD who have Alexithymia may be unable to identify their emotions and this will prevent them from recognising, sharing and coping with traumatic events they experience. The challenges of diagnosing PTSD in individuals with ASD was discussed by Chaplin, Spain and McCarthy (2020) who stated that some people with ASD may be unable to provide fully comprehensive accounts of their trauma and its impact, and might have difficulty communicating their thoughts and feelings, making a diagnosis challenging (Chaplin, Spain and McCarthy, 2020). These difficulties could also impact the ability of individuals with ASD to fully benefit from therapeutic interventions for PTSD due to the difficulties this population might experience in relaying trauma experiences and the trauma's impact to professionals.

2.3 6 Autism and Personality Disorder

Personality Disorder, according to the DSM-5, is an enduring and pervasive pattern of inner experience and behaviour that is inconsistent with the expectations of the individual's culture (APA, 2013). Personality Disorder appears in adolescence or early adulthood, leading to impairment and distress for the individual (APA, 2013). The DSM-5 contains 10 main differing personality disorders, which are divided into 3 clusters based on symptomatology similarities (APA, 2013). Cluster A includes schizoid, schizotypal, and paranoid personality disorders, with individuals having these disorders appearing eccentric or odd (APA, 2013). Cluster B contains antisocial, narcissistic, borderline, and histrionic personality disorder, with these disorders having presentations considered dramatic, erratic or emotional (APA, 2013). Cluster C includes obsessive-compulsive, avoidant, and dependent personality disorder, with affected individuals seeming anxious or fearful (APA, 2013). The Adult Psychiatric Morbidity Survey undertaken in 2014 found that 13.7% of their participants aged 16

years and over screened positive for a personality disorder (McManus et al., 2016). The DSM-5 states that gender differences are seen in personality disorders, with antisocial personality disorder being more frequently diagnosed in men, and with borderline, histrionic and dependent personality disorders being more commonly diagnosed in women (APA, 2013). Lugnegård, Hallerbäck and Gillberg (2012) explored the relationship between personality disorders and ASD and found that 48% of their sample of adults with autism met the diagnostic criteria for at least one personality disorder. This study highlights the need for people with ASD to be screened for personality disorder, and for individuals with personality disorder(s) to be assessed for ASD (Lugnegård, Hallerbäck and Gillberg, 2012).

Borderline Personality Disorder (BPD) was disclosed in the current study, and therefore will be briefly discussed. BPD is defined by the DSM-5 as a "*pattern of instability in interpersonal relationships, self-image, and affects, and marked impulsivity*" (APA, 2013, p.645). The Adult Psychiatric Morbidity Survey undertaken in 2014 found that 2.4% of their general population participants, aged 16-64 years, screened positive for BPD (McManus et al., 2016). Lai, Lombardo and Baron-Cohen (2014) proposed a BPD prevalence of between 0% and 9% in people with ASD. They stress the importance of careful differential diagnosis as the two conditions could have similarities in behaviours such as difficulties with interpersonal relationships, problems with affect regulation, and misattributing hostile intentions (Lai, Lombardo and Baron-Cohen, 2014). Lai, Lombardo and Baron-Cohen (2014) also contend that a diagnosis of BPD could be misdiagnosis of ASD and highlight this is more likely in women. Chaplin, Spain and McCarthy (2020) discussed BPD symptoms alongside ASD considerations to illustrate the relationship between the two conditions. For example, they contend that frantic attempts to avoid real or imagined abandonment could be related to difficulties individuals with ASD experience when creating social relationships, so when a relationship is formed the individual intensely fears that the relationship will end (Chaplin, Spain and McCarthy, 2020). Another example is that the inappropriate, intense anger or difficulty controlling anger seen in BPD may be connected to the emotional dysregulation seen in ASD (Chaplin, Spain and McCarthy, 2020). Therefore, a need for individual symptoms to be consider collectively rather than in isolation is required (Chaplin, Spain and McCarthy, 2020).

2.3.7 Autism and Gender Dysphoria

Gender Dysphoria is a diagnosis within this DSM-5 that refers to individuals who experience distress due to an incongruence between their experienced gender and their assigned gender (APA, 2013). For an adolescent or adult to obtain a diagnosis of Gender Dysphoria, there needs to a clear incongruence between the individual's experienced and assigned gender present for at least 6 months (APA, 2013). Examples of how this may manifest includes: a marked incongruence between one's experienced gender and their sex characteristics, a strong desire in the individual to be rid of their sex characteristics (due to the incongruence), a strong desire to have the sex characteristics of the other gender, a strong desire to be of another gender, and/or a strong belief of the individual that they have the typical feelings and reactions of another gender (APA, 2013). At least two of the above criteria are required for a diagnosis of Gender Dysphoria, as well as it being evident that the condition is causing significant distress or impairment in functioning (APA, 2013). Very little research has been done on the prevalence of Gender Dysphoria. However, a study by the Equality and Human Rights Commission (2012) found that 0.8% of their sample reported not identifying as the gender they were assigned at birth.

Limited research has been undertaken to explore the relationship between gender dysphoria and ASD, especially in adults (Glidden et al., 2019). A systematic review by Glidden et al. (2019) found that there is an increasing amount of evidence to support a co-existence between gender dysphoria and ASD, conveying there to be a high prevalence of ASD in people with gender dysphoria attending clinical services. Gender dysphoria in autism is also discussed by Fletcher-Watson and Happé (2019) who report a high-prevalence of non-normative gender identification in individuals with autism. Glidden et al. (2019) highlight the difficulty of diagnosing both conditions in individuals and the specialist skills required, stating that practitioners trained and experienced in both ASD and gender dysphoria is rare. Glidden et al. (2019) conclude that further research is required as there are significant gaps in understanding the potential relationship between gender dysphoria and ASD, and regarding appropriate assessment and treatment for gender dysphoria individuals with ASD.

2.3.8 Autism and Alcohol Dependency

Alcohol Dependence is a condition contained in the ICD-11, and is described as a disorder of the regulation of alcohol use, arising from continued or repeated alcohol use (WHO, 2019b). WHO (2019b) state that alcohol dependent individuals have an impaired ability to control alcohol consumption, with individuals having a strong desire to use alcohol accompanied by urges and cravings. According to the ICD-11, for a diagnosis to be given individuals normally have to evidence intermittent heavy drinking for at least 12 months but a diagnosis can be made after one month if the drinking is continuous (daily or almost daily) (WHO, 2019b). The ICD-11 requires practitioners to specify whether the individual's current alcohol use is continuous or episodic (WHO, 2019b). The corresponding diagnosis in the DSM-5 would be Alcohol Use Disorder where problematic alcohol use leads to significant impairment or distress (APA, 2013). When using the DSM-5 criteria, practitioners needs to specify the severity of the condition as mild, moderate or severe which is dependent on the number of symptoms the individual presents with (APA, 2013). The DSM-5 highlights that individuals with this disorder may continue to consume alcohol excessively despite knowing that continued drinking could cause significant physical (e.g. liver disease), psychological (e.g. depression), social, or interpersonal problems (APA, 2013). The 2014 Adult Psychiatric Morbidity Survey in England found that 1.2% of participants were dependent drinkers with men being more likely than women to drink at hazardous levels (McManus et al., 2016).

Boucher (2017) stated there was no evidence to suggest that individuals with ASD are more likely than others to be addicted to alcohol. However, in adults with ASD, Lugnegård, Hallerbäck and Gillberg (2011) found 7% of their sample to be alcohol dependent, and Hofvander et al. (2009) found 15 of their participants (12%) met the criteria for a substance use disorder related to alcohol. Tinsley and Hendrickx (2008) also discuss the relationship between Asperger Syndrome and alcohol use and debate if it is a dangerous combination or a successful coping strategy. Tinsley and Hendrickx (2008) discuss how alcohol use can be seen as beneficial to individuals with Asperger's; they discuss how people who have difficulty interacting and socialising can benefit from the loosening effects of alcohol and use it to assist accessing an "*otherwise impenetrable and overwhelming arena*" (i.e. a neurotypical world) (p.9). They discuss the role that alcohol can play in reducing anxiety; they also refer to

alcohol as a tranquilizer that can be used for someone who is constantly anxious and finds social situations unsettling (Tinsley and Hendrickx, 2008). The authors above are suggesting that alcohol use allows individuals with autism to mask or hide their autism in order to fit in. In relation to the development of alcohol dependency in ASD, Lalanne et al. (2015) proposed that presentations specific to ASD such as cognitive inflexibility and change-related anxiety may be vulnerability traits for the development of substance-use disorders.

2.3.9 Self-harm, suicidal ideation and suicidal behaviour in autism

In addition to the mental health disorders mentioned above, many individuals with autism self-harm or experience suicidality. Self-harm, also known as self-injurous behaviour, is where individuals undertake behaviours which harm themselves as a way to cope with difficult feelings that they are experiencing (Mental Health Foundation, 2016). Haith (2018) states that self-injurous behaviours vary in regularity and severity, with some individuals having regular ritualised patterns of self-harm. Examples of self-injurous behaviours include cutting, scratching, burning, biting, starving or bingeing on food, head-banging, taking overdoses and abusing of substances (alcohol and drugs) (Purkis, Goodall and Nugent, 2016). Within the DSM-5 a diagnosis titled Non-Suicidal Self-Injury is included to capture individuals with no suicidal intent, but intentionally causing self-inflicted damage to the surface of their body, which is likely to cause bleeding, bruising or pain (APA, 2013). The individual needs to undertake the above mentioned behaviour at least 5 or more days in the last year to receive this diagnosis (APA, 2013). The DSM-5 states that the individual must expect the self-injurous behaviours to either relieve negative feelings, resolve an interpersonal difficulty or induce a state of postive feeling (APA, 2013).

In relation to the purpose of self-harm, Purkis, Goodall and Nugent (2016) state that self-harm is usually a coping mechanism, rather than an attempt at suicide. It is believed that individuals with autism may undertake intentional self-harm in order to deal with emotional overload, communication difficulties or sensory sensitivities, but self-harm is also a common occurrence in individuals with mental health conditions (Purkis, Goodall and Nugent, 2016). In the general population, according to the Adult Psychiatric Morbidity Survey undertaken in 2014, the overall rate of self-harm in the adult population was 7.3%, with higher rates found in females (8.9%) compared to

males (5.7%) (McManus et al., 2016). In comparison, Lai, Lombardo and Baron-Cohen (2014) found up to 50% of individuals with ASD might be affected by self-injurious behaviours, proposing that these behaviours could signal frustration in people with autism due to reduced communication, anxiety, sensory differences and/or disruption of routine.

Additionally, individuals with autism can experience 'meltdowns' which for some may involve self-injurious behaviours. In the context of autism, a meltdown can be considered an "involuntary release of emotion" which is usually caused by a build-up of stress (Beardon, 2017, p.40) which surpasses the individuals ability to cope. Sensory overload is also known to be associated with meltdowns. Maguire (2014) reflected on his experience of sensory overload, which resulted in a sensory meltdown; he detailed how it felt like all his senses were on fire and how the experience was "unpleasant and unwelcome", with him needing time to recover afterwards (p.241). Meltdowns can manifest in a variety of ways (for example, verbally, physically or both) and can involve harm to self. As highlighted by Maguire (2014) above, meltdowns are a very distressing experience, with many individuals with autism reporting that they are unable to control their behaviours during a meltdown (Beardon, 2017). For individuals with autism and co-existing mental health conditions, reasons for self-harming may be related to the autism, mental health condition(s) or for reasons associated with both conditions. Self-harm in autism also poses a risk for misdiagnosis, with self-harming adults with autism being at risk of being incorrectly diagnosed with BPD leading to inappropriate treatment and feelings of invalidation (Purkis, Goodall and Nugent, 2016).

In addition to self-harm, suicidal ideation and suicidal behaviour are terms both commonly associated with both autism and mental health conditions. Suicidal ideation is a term that refers to thoughts about life not being worth living (Purkis, Goodall and Nugent, 2016), where suicidal behaviour is the undertaking of an action to end one's own life. In the general population, McManus et al. (2016) found that 5.4% of their adult participants reported suicidal thoughts in the past year, with 6.7% of the participants having made a suicide attempt at some point. When looking at autism, Lai, Lombardo and Baron-Cohen (2014) found that between 11% and 14% of individuals with autism have suicidal ideation, or have made a suicide attempt. In relation to diagnostic criteria, a diagnosis of Suicidal Behaviour Disorder is contained

within the DSM-5 which requires an individual to have made a suicide attempt wihin the last 24 months. A suicide attempt can be defined as a self-initated sequence of behaviours which the individual believes would lead to his/her own death (APA, 2013). This diagnosis should not be applied to individuals with suicidal ideation or to individuals undertaking preparatory acts for suicide (APA, 2013). The DSM-5 highlights that suicidal behaviour is seen in a variety of mental health disorders including (but not limited to) bipolar, major depressive disorder, anxiety disorders, alcohol use disorders, BPD, OCD, eating disorders and schizophrenia (APA, 2013). This, along with the elevated rates in people with autism, suggests that individuals with autism and co-existing mental health conditions could be at an even higher risk of suicidal behaviour. A challenge for future research is to establish to what extent ASD symptoms are associated with suicide attempts and the extent to which co-existing psychiatric disoders relate to suicidal behaviour (Richa et al., 2014). Richa et al. (2014) recommend that individuals with autism, regardless of severity or IQ, should be assessed for suicidal ideation and suicidal behaviour.

So far, this chapter has evidenced the increased prevalence of mental health conditions in individuals with autism, with more detailed information provided relating to the mental health conditions that were reported within the sample of the current study. This chapter will now provide a brief description of mental health services before moving onto discuss legislation and guidance relevant to mental health services for people with autism.

2.4 Mental Health Services

The above discussions of co-existing mental health conditions with autism highlights that many individuals with autism may require support from mental health services at some point in their lifetime. Mental health services are services that provide support and treatment to individuals with mental health difficulties. There are many treatment options with examples including self-help, counselling, psychotherapy and medication (NHS 111 Wales, 2020). It is important that people with mental illnesses are informed about the available options so that they can decide which treatment suits them best (NHS 111 Wales, 2020). NHS 111 Wales (2019) contend that mental health conditions can be difficult to treat as they can impact numerous aspects of an individual's life such as relationships, physical wellbeing, employment and housing. Due to the

complex nature of mental health, there are a number of mental health care professionals who help support those who are mentally unwell. Examples of professionals who provide mental health support include: General Practitioners (GPs), Mental Health Nurses, Psychologists, Psychiatrists, Counsellors, Psychotherapists, Occupational Therapists and Social Workers (NHS 111 Wales, 2019). In Wales, GPs and Local Primary Mental Health Support Services tend to deal with individuals who have less severe mental health difficulties (known as primary care). According to NHS 111 Wales (2020), each local authority in Wales will have a Local Primary Mental Health Support Service; this service undertakes tasks such as: undertaking mental health assessments for people who have been referred by a GP for further assessment, short-term interventions (e.g. stress management, counselling and family work), making onward referrals, providing guidance to GPs and other professionals in primary care regarding mental health, and provision of information to individuals about other support, e.g. support provided by third-sector organisations.

Individuals with more severe mental health difficulties are referred to secondary care; examples of teams within secondary care include community mental health teams and crisis resolution and home treatment teams. Community Mental Health Teams (CMHTs) support people with serious and complex mental health conditions living in the community, whereas Crisis Resolution and Home Treatment Teams (CRHTTs) treat people who are experiencing an acute and severe psychiatric crisis, such as a psychotic episode or suicide attempt (NHS 111 Wales, 2020). CRHTTs where possible aim to support/treat individuals in the community, and are responsible for planning post-crisis support with the aim of preventing future crises (NHS 111 Wales, 2020). Service users accessing secondary mental health services will either be considered outpatients or inpatients. Outpatients are service users being treated for mental health difficulties who are not required to stay in hospital or at a psychiatric unit for treatment but instead make trips to clinics or hospitals for treatment when needed (NHS 111 Wales, 2020). On the other hand, inpatients stay in hospital to receive treatment for a period of time. Inpatient stays can be voluntary where an individual agrees to an inpatient stay based on a recommendation from a mental health practitioner, or can be compulsory where an individual is admitted and detained under the *Mental Health Act 1983,* as amended in 2007 *(*NHS 111 Wales, 2020*).* Haith (2018) states suicide risk to be the main reason for compulsory admission to inpatient psychiatric services.

Under Part 2 of the *Mental Health (Wales) Measure 2010*, individuals accessing secondary mental health services will receive a Care and Treatment Plan (CTP). CTPs should consider the following eight areas of a person's life: (1) medical/psychological treatment, (2) personal care and physical wellbeing, (3) social, cultural or spiritual, (4) accomodation, (5) finance and money, (6) education and training, (7) work and occupation and (8) parenting and caring relationships (*Mental Health (Wales) Measure 2010).* Individuals who have CTPs will have an appointed Care Co-ordinator to monitor and co-ordinate their holistic care according to their CTP (NHS 111 Wales, 2020).

A recent report has compared the provision of mental health services in Wales to mental health services provided in other high-income European countries (Johnson, 2019). This report claimed that Wales was one of the best performing mental health services globally, with mental health being recognised in Wales as a priority health issue; however, compared to the other countries Wales performed poorly in relation to the occupation of beds, having an available specialist workforce, and community contacts (Johnson, 2019). It was claimed by Johnson (2019) that Wales had fewer beds allocated for mental health services for both children and adults compared to other countries, with these beds being close to capacity. Additional concerns were also raised about the size of the specialist workforce in Wales. The document highlights the need for a well-trained workforce when supporting individuals with mental health difficulties, and highlights the resource intensive (time and money) nature of providing such support (Johnson, 2019). However, the report did acknowledge that Wales is successful in providing support to those in high levels of need (Johnson, 2019). The importance of involving services users with current or past mental health difficulties, also known as experts by experience, in the design or revision of services was emphasised in the report by (Johnson, 2019).They stated that involving service users allows things to be seen from a non-medical viewpoint, where other issues such as accessibility of services, lack of public transport to appointments, appropriate times for appointments, and opportunities for social activities with peers, can be discussed ensuring a more person-centred service (Johnson, 2019). The report states that a shift from measurable targets is needed; more emphasis should be given to the voice of experts by experience who are best placed to evaluate the effectivess of the services they are receiving (Johnson, 2019).

The current project is exploring mental health services specifically for people with autism. Fletcher-Watson and Happé (2019) state that treatment and support for people with autism is often created and evaluated without those living with autism. Based on the report by Johnson (2019) mentioned above, it is imperative for people with autism to be included in the process of developing and evaluating mental health services. Autistica (2016) undertook a project to establish research priorities for autism research; one research priority contained within the report was: "*how should service delivery for autistic people be improved and adapted in order to meet their needs?"* (Autistica, 2016, p.4). Through involving service users, as suggested by Johnson (2019), hopefully services (such as mental health services) can be adapted and improved to meet the needs of individuals with autism. According to Murphy et al. (2016), there is an urgent need for improved mental health care for adults with autism, emphasising that research is needed to obtain a better understanding of the needs of adults with autism. The importance of obtaining the views of people with autism in research and service development is stressed (Murphy et al., 2016).

The following section will discuss legislation and guidance applicable to the current study and mental health service provision. The legislation that will be discussed includes the *Mental Health Act 1983, the Human Rights Act 1998, the Mental Capacity Act 2005, Equality Act 2010 and the Mental Health (Wales) Measure 2010*. Following this, the relevant NICE guidance as well as the Refreshed Autistic Spectrum Disorder Action Plan (Welsh Government, 2016b) will be considered.

2.5 Relevant Legislation

2.5.1 Mental Health Act 1983

The *Mental Health Act 1983* is relevant to this study, as this Act governs the assessment, treatment and rights of people with a mental health condition (NHS, 2019a). NHS (2019a) highlight that most individuals who are treated in hospital, or in another mental health facility, do so voluntarily. However, when people with mental health disorders need urgent treatment and are at risk of harming themselves or others, the *Mental Health Act 1983* permits individuals to be sectioned, and treated against their will if necessary (NHS, 2019a). Specifically in Wales, a Code of Practice had been developed by the Welsh Government (2016a) to provide guidance to professionals on how they should proceed when undertaking duties relating to the

Mental Health Act 1983. The Code of Practice applies to the care and treatment provided to all patients in Wales who are subject to the Act; this includes individuals who are liable to be detained, those who are subject to community treatment orders and those who are received into guardianship (Welsh Government, 2016a). A specific chapter within the Code of Practice has been dedicated to providing guidance on applying the Mental Health Act 1983 to individuals with autism or learning disability (Welsh Government, 2016a).

2.5.2 Human Rights Act 1998

This Act incorporated the rights and freedoms contained within the European Convention on Human Rights into UK law. The *Human Rights Act 1998* places a legal duty on public authorities, such as the NHS, to protect and respect an individual's rights; in other words, it is unlawful for a public body to act in a way that is incompatible with a convention right. Within the *Human Rights Act 1998*, there are 16 rights, with five being particularly applicable in relation to health and care services that individuals may be accessing (The British Institute of Human Rights, 2017). These five rights are: (1) right to life, (2) right to not be treated in an inhuman and degrading way, (3) right to liberty, (4) right to respect for private and family life, home and correspondence, and (5) the right not to be discriminated against when depending on other rights contained within the *Human Rights Act 1998* (The British Institute of Human Rights, 2017). Each right will now be discussed in relation to health services. The right to life involves authorities not deliberately taking away an individual's life and also taking reasonable steps to protect their life if it is at risk, from themselves or others (The British Institute of Human Rights, 2017). The right to be free from inhuman and degrading treatment protects individuals against very serious harm such as abuse, neglect, use of excessive force to restrain an individual, lack of care or medication leading to extreme suffering (The British Institute of Human Rights, 2017). The right to liberty is a right that can be breached by health and care services under the *Mental Health Act 1983* and *Mental Capacity Act 2005* when there is deemed to be a risk to the individual or others. In relation to health services, the right to respect for private and family life, home and correspondence can relate to the confidentiality of personal information, and an individual being involved in decisions regarding their care and treatment (The British Institute of Human Rights, 2017). This right can be breached when there is a risk to the service user or others. The right not to be discriminated against when

depending on other rights contained within the *Human Rights Act 1998* ensures that people accessing services are treated equally; receiving care of a lower standard due to having a disability would be a breach of this right. In summary, human rights ensure that people are treated fairly, with respect and dignity, and that people are listened to and have a say over their lives (The British Institute of Human Rights, 2017).

2.5.3 Mental Capacity Act 2005

This piece of legislation is relevant to the study as the issue of mental capacity can at times be necessary to consider for individuals who have mental health conditions. The Mental Capacity Act 2005 applies to individuals aged 16 and above, and the purpose of the Act is to protect and empower individuals who may lack the mental capacity to make decisions for themselves (NHS, 2018). The Act emphasises that a person cannot be regarded as unable to understand information relevant to a decision if the information can be provided to the person in an alternative way that they can understand, e.g. by simplifying the language used or by using visual communication aids) (*Mental Capacity Act 2005*). The principle that individuals must be assumed to have capacity unless they are assessed as not having capacity is emphasised in the Act; but where a decision has to be made on someone's behalf, the decision must be made in the individual's best interests in the least restrictive way (*Mental Capacity Act 2005*). *The Mental Capacity Act 2005* states that a person is unable to make a decision if they cannot: (1) understand the information relevant to making a decision, (2) retain the information, (3) use or weigh the relevant information as part of the decision-making process, and/or (4) communicate their decision (by any means of communication).

2.5.4 Equality Act 2010

The *Equality Act 2010* is a piece of legislation that replaced the previous anti-discrimination laws with one Act to simplify the law and remove inconsistencies (Government Equalities Office, 2010). The Act is relevant to the current research as it legally defines disability as a protected characteristic (*Equality Act 2010).* The *Equality Act 2010* states an individual has a disability if they have a physical or mental impairment that has a significant, long-term adverse effect on the individual's functioning. Due to this, people with autism and individuals with enduring mental health difficulties would be considered disabled, and therefore would be legally protected

against discrimination under this legislation. The *Equality Act 2010* is also of relevance to this study as it established the requirement for reasonable adjustments for individuals with disabilities. The Act states that where a disabled person is placed at a substantial disadvantage compared to someone who is not disabled, reasonable steps must be taken to remove the disadvantage (*Equality Act 2010).* Additionally, service providers have an anticipatory duty to make appropriate reasonable adjustments, meaning that services must anticipate the needs of people with disabilities and make the appropriate adjustments (*Equality Act 2010).* The *Equality Act 2010* also specifies that reasonable steps should be made to ensure that information is provided to individuals with disabilities in an accessible format. If a provision, criterion or practice fails to make a reasonable adjustment, then that could be considered discrimination (*Equality Act 2010).*

2.5.5 Mental Health (Wales) Measure 2010

The relevance of the *Mental Health (Wales) Measure 2010* to the current study is that it places requirements on local health boards to provide mental health services in a certain way. This piece of Welsh legislation places legal duties on local health boards and authorities in regards to the assessment and treatment of mental health conditions, as well as improving access to independent mental health advocacy for individuals with mental health problems (NHS Wales, n.d.). The *Mental Health (Wales) Measure 2010* governs: (1) the delivery of local primary mental health support services, (2) the co-ordination of and planning for secondary mental health service users, (3) the arrangements for assessment of former users of secondary mental health services, and (4) oversees independent advocacy for persons detained under the *Mental Health Act 1983* or those receiving in-patient hospital treatment for their mental health (*Mental Health (Wales) Measure 2010*). The Measure is broken down into 4 main parts. The first part of the Measure was to ensure that more mental health services were available within primary care with a joint Local Primary Mental Health Support Service (local health board and authority) being delivered within and alongside GP settings (NHS Wales, n.d.). The service should provide assessment, short-term intervention, information and advice, and onward referral (when required) (NHS Wales, n.d.). Part 2 of the Measure ensures that people of all ages who are in receipt of secondary mental health services receive an individualised Care and Treatment Plan (CTP), and have an appointed Care Co-ordinator (NHS Wales, n.d.).

The Measure stipulates that a recovery model is followed and that service users should be actively involved in the development of their CTP (NHS Wales, n.d.). The third part of the Measure allows individuals to self-refer directly back into secondary mental health services if they have previously been discharged from secondary services; this removes the requirements of the individual having to go back to the GP to be referred back in (NHS Wales, no date). Part 4 of Measure guarantees that all inpatients in Wales who are receiving assessment or treatment are entitled to apply for support from an Independent Mental Health Advocate; this obligation applies to those in hospital voluntarily as well as individuals who are governed by the *Mental Health Act 1983* (NHS Wales, n.d.).

2.6 Guidance for services

The National Institute for Health and Care Excellence's (NICE) role is to improve outcomes for people accessing the NHS and other public health services in addition to social care services (NICE, 2020a). NICE (2020a) do this by creating guidance which is evidence-based to advise practitioners, and by developing quality standards for those providing services. Relevant to the current study, NICE have created a quality standard for autism (NICE, 2014) and a clinical guideline for Autism Spectrum Disorder in adults (NICE, 2016) which can also be displayed as a clinical pathway (NICE, 2020b).

NICE (2014) states that a person-centred, integrated approach to delivering services is central to providing high-quality care to people with autism. The guideline states that peoples' needs and preferences should be considered in relation to their care/support (NICE, 2016). NICE (2016) specify that people with autism should be given the opportunity to make informed decisions about the care they receive, in collaboration with their healthcare practitioners. When individuals do not have the capacity to make their own decisions, professionals should work in accordance with the *Mental Capacity Act 2005*, discussed previously.

It is argued that all practitioners who work with people with autism, or who have a role in assessing, caring for and treating individuals with autism, should be sufficiently and appropriately trained (NICE, 2014). The guidance also recommended that individuals with autism should be involved in the delivery of autism training to practitioners (NICE, 2014). NICE (2014) provides quality standards that set out priority areas for quality

improvement for health and social care. The quality standards comprise of a set of statements on how quality could be improved, and information on how to measure progress made (NICE, 2014). These statements are not mandatory but can be utilised to deliver services that provide high-quality care (NICE, 2014). Specifically, in relation to autism, NICE (2014) detailed 8 statements for delivering care/services to people with autism. These statements and further details are provided below.

Statement 1: "People with possible autism who are referred to an autism team for a diagnostic assessment have the diagnostic assessment started within 3 months of their referral".

The NICE (2014) quality standard stresses the importance of an assessment being undertaken as soon as possible so that correct interventions, advice and support can be offered to the individual. Teams conducting autism assessments for individuals should be a specialist integrated autism team and should be part of the local autism diagnostic pathway (NICE, 2014). NICE (2014) suggest that a local autism team for adults should consist of the following professionals: clinical psychologists, primary care services, nurses, occupational therapists, psychiatrists, social workers, speech and language therapists and support staff. During an autism assessment, the professional should enquire about and assess the following: core autism signs and symptoms, developmental history, behavioural problems, the individual's functioning, past and present co-existing conditions (mental and physical), co-existing neurodevelopmental disorders and sensory sensitivities (NICE, 2014).

Statement 2: "People having a diagnostic assessment for autism are also assessed for coexisting physical health conditions and mental health problems".

It is important to acknowledge that individuals with autism may have co-existing conditions (mental or physical). It is highlighted by NICE (2014) that if the co-existing conditions go unrecognised, and therefore untreated, the co-existing condition(s) will further impair the individual's functioning. The social communication challenges seen in autism mean that some people with autism may find it difficult to access health and social care, and to communicate what they need (NICE, 2014). NICE (2014) states that practitioners should also assess for co-existing conditions when undertaking autism assessments, and that the findings of the assessments should be shared with

the individual and also be considered when developing a personalised plan. Service providers need to ensure they have staff with suitable experience to allow this to happen (NICE, 2014). Co-existing conditions which should be considered are other neurodevelopmental disorders, co-existing mental health disorders, neurological disorders, physical health conditions, communication problems and sensory sensitivities (NICE, 2014).

Statement 3: "People with autism have a personalised plan that is developed and implemented in a partnership between them and their family and carers (if appropriate) and the autism team".

Individuals with autism have varied needs; some requiring intense support and some not needing ongoing support (NICE, 2014). A personalised plan helps to ensure that the indivdiual's care is coordinated by considering the findings of diagnostic assessments, by incorporating the needs of the individual with autism, and by recognising the individual's strengths (NICE, 2014). NICE (2013) stresses the importance of practitioners working in partnership with the individual with autism to create and implement the personalised plan. The personalised plan needs to be updated and reviewed as required (NICE, 2014). A personalised plan should: cover any requirement for post-diagnostic support, detail relevant interventions and support (as well as the associated timescales), cover preventative action to address triggers, and contain any interventions advised for co-existing conditions if identified (NICE, 2014).

Statement 4: "People with autism are offered a named key worker to coordinate the care and support detailed in their personalised plan".

Due to individuals with autism having broad and differing needs, their care can often involve a number of providers delivering services (NICE, 2014). A named key worker can undertake the role of ensuring an individual receives an integrated package of care, based on the personalised plan, and can ensure the ongoing review of the plan (NICE, 2014). If the individual accepts the offer of having a named key worker, the individual should be involved in deciding which professional is most appropriate for that individual (NICE, 2014). Practitioners need to ensure that people with autism are offered a named key worker, and service providers needs to ensure they have the staffing capacity and protocols in place to faciliate this (NICE, 2014). Adults currently

receiving care should have a named key worker; for individuals not receiving ongoing care, a member of the primary care team could be the designated key worker (NICE, 2014).

Statement 5: "People with autism have a documented discussion with a member of the autism team about opportunities to take part in age-appropriate psychosocial interventions to help address the core features of autism".

Evidence suggests that psychosocial interventions can help manage ASD symptoms and therefore should be considered for people with autism (NICE, 2014). Different psychosocial interventions are available, and decisions about suitability should be dependent on the age and needs of the individual (NICE, 2014). NICE (2014) highlight the variable availability of psychosocial interventions for individuals with autism. NICE (2016) make recommendations in relation to psychosocial interventions targetting the core features of autism, and psychosocial interventions to improve an individual's life skills.

Statement 6: "People with autism are not prescribed medication to address the core features of autism".

NICE (2014) state that medications are not recommended to treat the core features of ASD; antipsychotics, antidepressants, anticonvulsants, and drugs designed to improve cognitive function are listed as medications not recommended. However, it is acknowledged by the quality standard that medication may be appropriate for the short-term management of challenging behaviour in people with autism (NICE, 2014). NICE (2014) state that practitioners should ensure they do not prescribe medication to address the core symptoms of autism, and should instead consider other options such as psychosocial interventions.

Statement 7: "People with autism who develop behaviour that challenges are assessed for possible triggers, including physical health conditions, mental health problems and environmental factors".

NICE (2014) provide Emerson's (2001) definition of challenging behaviour, with challenging behaviour being considered as behaviour that is considered culturally abnormal and of such intensity, frequency or duration that the person or others could be at risk of harm, or behaviour which is likely to result in the individual being denied

admittance to community venues. Challenging behaviour can sometimes be seen in individuals with autism, and the causes of the behaviour can be multifactorial, involving mental health difficulties, physical health conditions and environmental influences (NICE, 2014). Assessments should take all these factors into account as well as considering the risk of harm to the individual and/or others, before any intervention for the individual is decided upon (NICE, 2014). Examples of factors that may trigger an individual include: physical disorders, the physical and social environment, co-existing mental health difficulties, communication challenges, and changes to routine or personal circumstance (NICE, 2014). It is important to note here that whilst NICE use the term 'challenging behaviour', these behaviours are labelled as challenging due to the fact that they are perceived/experienced by others to be challenging; however, the person exhibiting the behaviour is not doing so deliberately to challenge. The Challenging Behaviour Foundation (2020) contends that there is always a reason for challenging behaviour(s) and that these behaviours should be viewed as a form of communication, a way for an individual to communicate that they have an unmet need.

Statement 8: "People with autism and behaviour that challenges are not offered antipsychotic medication for the behaviour unless it is being considered because psychosocial or other interventions are insufficient or cannot be delivered because of the severity of the behaviour".

NICE (2014) stress that psychosocial interventions or interventions to address triggers should always be the first-line intervention for challenging behaviour in individuals with autism. However, it is acknowledged that sometimes these interventions may not be sufficient on their own or may not be possible due to the severity of the individual's challenging behaviour (NICE, 2014). When this is the case, a trial of antipsychotic medication may be undertaken in an attempt to manage the challenging behaviour, but medication use should be monitored by a specialist (NICE, 2014).

In addition to the eight quality statements discussed above, NICE (2016) provide guidance specifically in relation to interventions for coexisting mental health disorders in autism. It is emphasised here that professionals delivering intervention to adults with autism and co-existing mental health disorders should have an understanding of the core features of ASD and their impact on the treatment of the co-existing mental health

disorder (NICE, 2016). In addition, professionals should consider obtaining advice from a specialist autism team regarding how interventions should be delivered and adapted for this specific population (NICE, 2016). Psychosocial and pharmacological interventions for co-existing mental health disorders in autism are discussed in the guidance (NICE, 2016). In relation to both psychosocial and pharmacological interventions for this population, NICE (2016) suggest offering the interventions informed by existing NICE guidance for the specific co-existing disorder. Specifically, in relation to psychosocial interventions, NICE (2016) discuss adaptions that should be made to the delivery of cognitive and behavioural interventions for this specific population. The adaptions include: (1) a more concrete, structured approach with greater use of written and visual information, (2) placing emphasis on changing behaviour and using behaviour as the starting point of intervention, (3) making rules explicit and explaining context, (4) avoiding excessive use of metaphor, ambiguity, or hypothetical situations, (5) involving a family member/partner/carer/professional (if the individual consents) and (6) maintaining the person's attention by offering regular breaks and including their special interests in therapy, if possible (NICE, 2016).

In addition to the guidance from NICE, the Welsh Assembly Government (2008) created a Strategic Action Plan for ASD, with an updated version released in 2016 (Welsh Government, 2016b). The updated Strategic Action plan reaffirmed the Welsh Government's commitment to improving the lives of individuals with autism; however, a proposed Autism (Wales) Bill was not supported by the Welsh Government in 2019 (National Assembly for Wales Senedd Research, 2019). However, during discussions of the Bill, the current challenges people with autism (and their families) experience when trying to access support was deemed unacceptable, and something that needed addressing (National Assembly for Wales Senedd Research, 2019). The Refreshed Strategic Action Plan (Welsh Government, 2016b) aims to ensure that the needs of individuals with autism (and their families/carers) are understood, and that individuals are supported to achieve their own wellbeing outcomes and lead fulfilling lives. The Strategic Action Plan (Welsh Government, 2016b) with an accompanying delivery plan (Welsh Government, 2018) identified three main areas for action: (1) assessment and diagnosis, (2) meeting support needs, and (3) awareness raising, information and training. Relevant to the current study, the Welsh Government (2016b) stress the importance of practitioners identifying both autism and the co-existing condition(s) so

that the care/support provided best meets the individual's needs. They also highlight that individuals who have autism with a co-existing condition can have complex difficulties and may not respond to traditional approaches (Welsh Government, 2016b). Areas identified which could be improved in the future include: improving the timeliness of assessment and subsequent diagnosis, providing consistent services across Wales, and a focus on supporting individuals with autism who have significant support needs, but may not be eligible for social care services (Welsh Government, 2016b). The Refreshed Strategic Action Plan states that health boards should consider NICE guidance when planning autism services as they set the benchmark for what good services should provide (Welsh Government, 2016b). In relation to assessment and diagnosis, the Welsh Government (2016b) want individuals with autism (children and adults) to have access to timely referral, assessment and post-diagnostic services which meet the needs of the individual. Regarding meeting support needs specific to healthcare, the Strategic Action Plan highlights that autism is often overlooked by healthcare and this creates barriers to accessing support and services; unmet support needs can cause difficulties to escalate to crisis point resulting in the individual needing intensive interventions (Welsh Government, 2016b). In relation to the current study and regarding awareness raising, information and training, the Strategic Action Plan emphasised an ongoing need to raise awareness of autism across a range of professions to ensure that professionals know the key signs of autism and how to adapt their practice/services in order to meet individual needs (Welsh Government, 2016b).

2.7 Summary

This chapter has evidenced that individuals with autism are at higher risk of developing mental health conditions than the general population. The higher prevalence of mental health difficulties in this population would suggest that many individuals with autism are likely to require support from mental health services during their lifetime, which highlights the need for adult mental health services to be accessible and appropriate for adults with autism. This chapter also highlighted legislation and guidance relevant to the supporting of adults with autism and mental health conditions. The following chapter will provide a review of the current literature exploring the needs and experiences of adults with autism of accessing healthcare.

Chapter Three:
The Healthcare Experiences of Adults with Autism

3.1 Introduction

The previous chapter set the context for the current research project, discussing Autism Spectrum Disorder (ASD), co-existing autism and mental health disorder(s), and relevant legislation and guidance. This chapter will review and present the existing literature available on the healthcare service needs and experiences of adults with autism relevant to Phase 1 of the current study.

3.2 Literature Review 1

In an effort to gain an understanding of the service experiences of adults with autism, the aim of this chapter is to review existing literature through searches of several databases and additional sources. According to Gray (2018), a literature review is the evaluation of documents on a topic that contain information and evidence relevant to a particular piece of research. Likewise, Cope (2014) states that a literature review should: tell the reader what is known about a certain research topic, identify gaps in the literature, and share the strengths and weaknesses of studies presented in the review.

The literature review contained within this chapter is the first of two literature reviews; this chapter will explore the healthcare needs and experiences of adults with autism, as where the second literature review contained in the following chapter will examine the available literature in relation to healthcare professionals' knowledge of ASD. Both literature reviews have been undertaken in a systematic way, but do not meet the criteria for a systematic review. A systematic review is defined by Gray (2018) as a replicable process that aims to limit researcher bias by identifying, evaluating and synthesising all studies relevant to a research question. Both literature reviews contained within this thesis drew on clear research questions, used pre-defined search terms, had inclusion and exclusion criteria, and therefore were undertaken in a way that would allow for replication. However, Charrois (2015) stated that systematic reviews require at least two researchers to be involved in checking the eligibility of potential studies (based on the predefined inclusion and exclusion criteria), as well as

the extraction of data from eligible papers. Therefore, the literature reviews contained within this thesis cannot be considered systematic reviews due to the fact that only one researcher (the PhD student) screened the studies and extracted the data from the papers. This chapter will now provide the details of the search strategy followed for the first literature review and share the review's findings.

3.3 Scope of Literature Review 1 (Phase 1)

The literature review undertaken aimed to locate literature that aligned with the overarching research questions/aims of the current study in order to identify a gap in the knowledge that this study seeks to fill. The research question relevant to Phase 1 of the current study that could be explored through reviewing the literature is as follows:

What are the needs and experiences of service users with co-existing autism and mental health difficulties accessing adult mental health services? (Phase 1 Literature Review)

An initial search of the literature using key words such as 'autism/ASD and mental health', 'autism/ASD and mental health services' and 'autism/ASD service experiences' on Google Scholar was undertaken to establish the extent of available literature and to identify further key words that could be used for the final literature search. This initial search indicated that there was very limited literature specifically on the needs/experiences of adults with autism accessing mental health services/support (only three papers met the inclusion criteria of the current review); therefore the scope of the literature review was expanded to include any healthcare needs/experiences, not just those of mental health services. Therefore, for the purposes of Literature Review 1 contained within this chapter, the scope of the review was expanded to answer the following research question:

What are the needs and experiences of service users with ASD accessing healthcare? (Phase 1 Literature Review)

3.4 Method for Phase 1 Literature Review

3.4.1 Search Strategy

Eight electronic databases were searched in a systematic way to identify relevant publications: Science Direct, CINAHL, MEDLINE, ProQuest Psychology, ProQuest Nursing & Allied Health, PsychInfo, ASSIA, and PubMed. ResearchGate and Google Scholar were also searched for pertinent articles using combinations of the search terms utilised for the database searches. Review parameters required all articles to be: published between January 2013 and December 2020, written in English, peer-reviewed, and available as full-text version. Only papers from 2013 onwards were included as this was the year in which the DSM-5 created the umbrella diagnosis of ASD (APA, 2013). The inclusion of papers between 2013 and 2020 ensured that the literature was contemporary in the way that autism spectrum conditions are viewed and portrayed. The search terms and Boolean operators used for the literature searches are shown in the Figure 1.

Figure 1: Search terms used for literature search

After searching the databases using the above search terms, 511 records were identified. The table below (Table 2) illustrates the number of total articles returned in each database.

Table 2: Total number of hits per database

Database	Total number of hits
Science Direct	55
CINAHL	29
MEDLINE	42
ProQuest Psychology	54
ProQuest Nursing and Allied Health	36
PsychInfo	88
ASSIA	62

PubMed	145
Total number of hits (all included databases)	**511**

Of these 511 articles, 187 duplicates were removed, leaving 324 articles to be screened. Four additional articles were identified through ResearchGate and Google Scholar.

3.4.2 Inclusion and Exclusion Criteria

The inclusion and exclusion criteria that were followed when screening the literature can be found below (Table 3). Both empirical and non-empirical papers were included if they met the below criteria due to there being limited research in the field.

Table 3: Inclusion and exclusion criteria for literature search

Inclusion Criteria	Exclusion Criteria
▪ Articles must be about individuals with ASD or include participants with ASD ▪ Articles must be about service users' experiences of healthcare, access to healthcare or service needs ▪ Articles must be related to healthcare services (but can include additional services) ▪ Articles must be available in English ▪ Articles must be available as a full-text version through sources accessible online to the researcher	▪ Articles that are not specific to ASD ▪ Articles that only include people with ASD under the age of 18 years ▪ Articles that only include parent/caregiver/supporter/clinician perspectives ▪ Articles only discussing prevalence or rates of service use ▪ Articles measuring the effectiveness of different interventions (e.g. drug therapy, talking therapies)

3.4.3 Screening Process

A PRISMA flow diagram (Figure 2) has been completed to illustrate the review process, including the number of records identified, included and excluded (Moher et al., 2009).

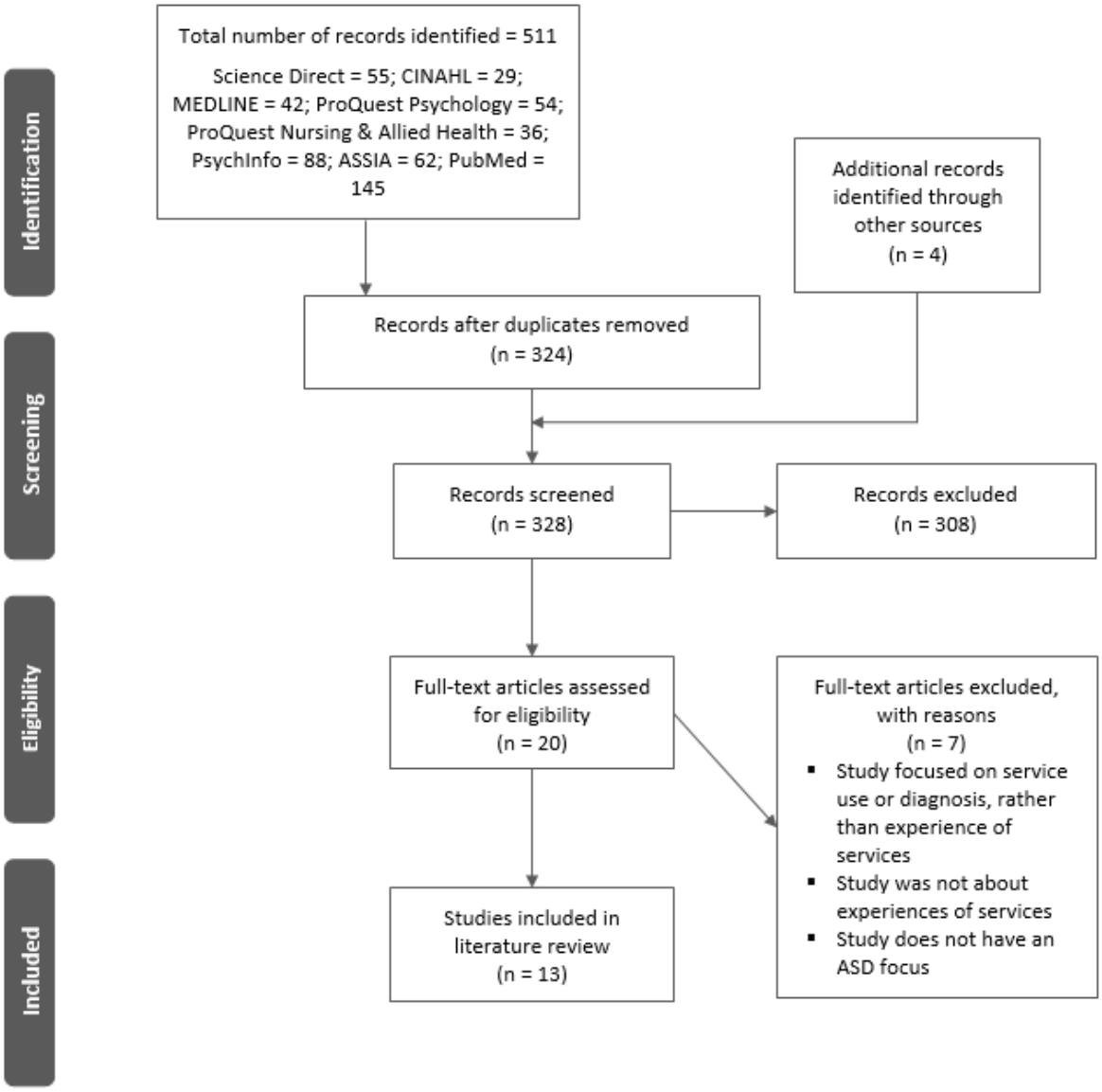

Figure 2: PRISMA flow diagram

As shown in the PRISMA flow diagram above, 308 records were excluded after being screened at title/abstract level, with 20 records being screened at full-text level. Reasons for exclusion at the title/abstract level included, but are not limited to, papers: not being relevant to autism, focusing exclusively on intellectual disability rather than autism, exploring the biology of autism, being about autism in children, relevant to

caregivers of individuals with autism, and evaluating interventions for people with autism. The literature search and screening process identified 13 papers that fulfilled the inclusion criteria for the search. The majority of the studies included were conducted in the United States (N = 5) and the United Kingdom (N = 4), followed by Canada (N = 2), Australia (N = 1) and Germany (N = 1). The thirteen papers consisted of mixed-method studies (N = 4), qualitative studies (N = 4), quantitative studies (N = 3), a systematic review and a review article.

Critical appraisal was undertaken on all but one of the identified studies using Critical Appraisal Skills Programme (CASP) Checklists (Critical Appraisal Skills Programme, 2018a; Critical Appraisal Skills Programme, 2018b). The review article by Barber (2017) was not critically appraised using an appraisal tool as this paper was not an empirical piece, and therefore could not be critically appraised as research. However, the contribution of the paper was highlighted in Appendix 2. The CASP Qualitative Studies Checklist (CASP, 2018a) was utilised and slightly modified so that it could be applied to qualitative, quantitative and mixed-method papers. For example, question two on the checklist had to be adapted from 'Is a qualitative methodology appropriate?' to 'Is the chosen methodology appropriate?' (CASP, 2018a). Additionally, for quantitative studies, question 6 ('Has the relationship between researcher and participants been adequately considered?') was not completed as the influence of the researcher on participants is less significant compared to qualitative studies. One of the studies included in this critical appraisal was a systematic review (Bradshaw et al., 2019); therefore, this paper was critically appraised using the CASP Systematic Review Checklist (CASP, 2018b). Additionally worth noting, Beresford et al. (2020) was included in the critical appraisal, but with the focus being placed on Chapter 7 of their paper rather than the whole publication. The research undertaken by Beresford et al. (2020) involved many facets, not all of which were relevant to the current literature review. Therefore, only information contained within Chapter 7 of their report (service user experiences) was included in this literature review, and therefore this is the chapter that was critically appraised. To view the completed CASP Checklists, please see Appendix 2.

After critical appraisal had been undertaken, the 13 papers were synthesised narratively and grouped into four separate categories. The first category (consisting of five papers) contained papers looking broadly at the healthcare needs and

experiences of adults with autism, funnelling down to category four (containing three papers) containing articles which specifically explored the mental health service experiences of adults who have co-existing autism and mental health difficulties (the focus of the current study). The second category (two papers) explored the experiences of adults with autism in relation to patient-, provider- and system-level factors in healthcare, with the third category (three papers) specifically investigating barriers to healthcare for individuals with autism. The below infographic (Figure 3) visually depicts the funnelling of findings from the general healthcare experiences of adults with autism (Category 1) down to their experiences of accessing/receiving mental health support. Additionally, see Table 4 below for category titles and corresponding articles.

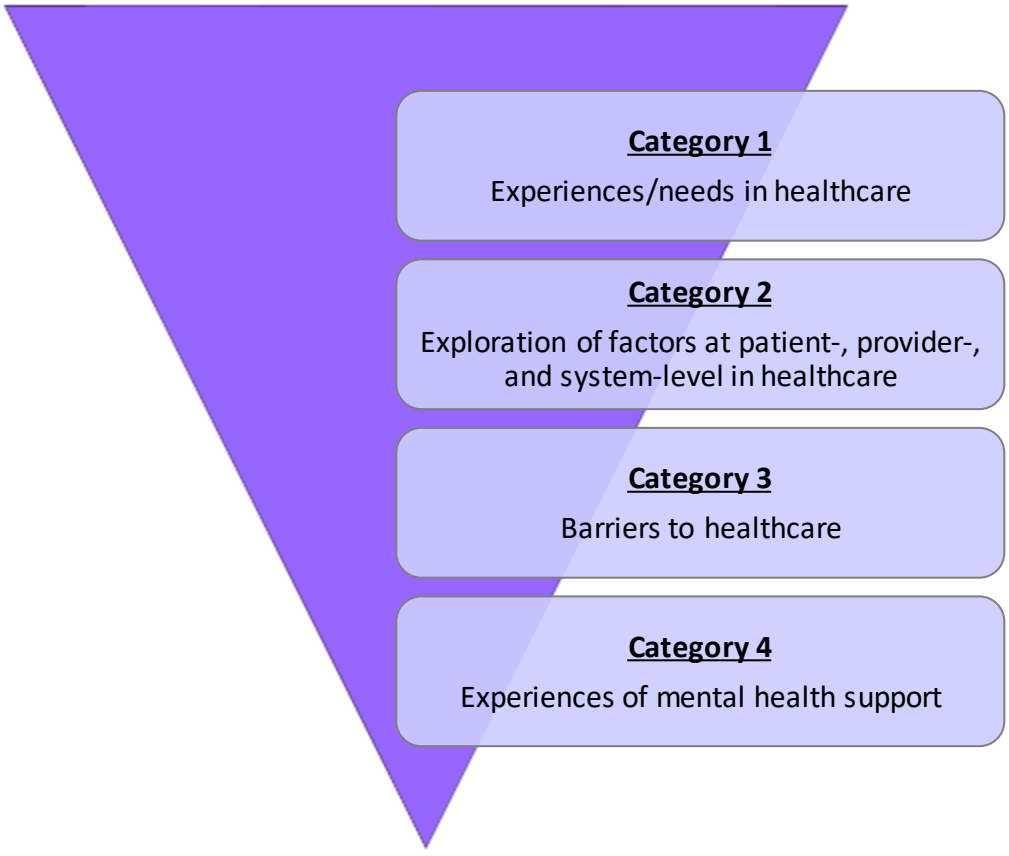

Figure 3: A visual depiction of category relevance in relation to study research question

Table 4: Literature Review Categories

Category Number	Category Title	Corresponding Articles
1	Experiences and needs in healthcare	Nicolaidis et al. (2013), Barber (2017), Tint and Weiss (2017), Saqr et al (2017) & Beresford et al. (2020)
2	Exploration of patient-, provider-, and system-level factors in healthcare	Nicolaidis et al. (2015) & Bradshaw et al (2019)
3	Barriers to healthcare	Dern and Sappok (2016), Vogan et al. (2017) & Raymaker et al (2017)
4	Experiences of mental health support	Crane et al. (2018), Camm-Crosbie et al. (2018) & Maddox et al. (2019)

Within each category, consistent key findings will be highlighted and discussed before a category summary is provided. The categories have been discussed such that the literature moves from broadly describing the needs and experiences of adults with autism in healthcare to specifically exploring the needs and experiences of this population in relation to accessing mental health support, which is an aim of this thesis.

3.5 Phase 1 Literature Review Findings

3.5.1 Category 1 – Experiences and needs in healthcare

This category contains studies which either investigated the healthcare experiences of adults with autism, or explored the needs of this population. Five articles were identified which fell within this category. Two articles explored healthcare experiences generally, one investigated service experiences (including health), another focused specifically on primary care settings with the final one exploring experiences of accessing Specialist Autism Teams (SATs). The first study to be discussed is a quantitative study by Nicolaidis et al. (2013) comparing healthcare experiences of adults with and without autism. The second paper, Barber (2017), discusses the healthcare needs of adults with autism, focusing primarily on adults with higher levels

of functioning. Study three by Tint and Weiss (2017) qualitatively explored service experiences of adults with ASD, specifically women. The fourth article, Saqr et al. (2017), investigated the needs of adolescents and adults with ASD within primary care settings. Study five, Beresford et al. (2020) involved an evaluation of specialist autism teams' (SATs) provision of care/support for adults with autism without learning disabilities. The above mentioned studies will be discussed below in the context of consistent findings.

3.5.1.1 Meeting the needs of adults with autism

Barber (2017) discusses the healthcare needs of adults with autism, specifically those with Asperger's Syndrome/High Functioning Autism, and argues that due to the fact that approximately 1% of the general population are on the autism spectrum it would be reasonable to expect care providers to be aware of this population's specific needs, and to modify services accordingly. Nicolaidis et al. (2013) found that adults on the spectrum had significantly higher odds of unmet healthcare needs related to physical health, mental health and prescription medications compared to adults who were not on the spectrum. This illustrates that adults with autism experience greater unmet healthcare needs (Nicolaidis et al., 2013). Barber (2017) provided a table of needs for people on the autism spectrum and included corresponding ways health professionals can help meet these needs. One example was that a person on the spectrum may have a very literal understanding of language, and health professionals can help by keeping language simple ("say what you mean and mean what you say") as a way to assist the person (Barber, 2017, p.422). Therefore, this paper offered practical ways in which health professionals can adapt their practice to make services more autism-friendly.

The extent to which individual's needs were met within Specialist Autism Teams (SATs) was explored by Beresford et al. (2020). Participants were allocated into one of three groups based on their responses: needs predominantly met, mixed experience (met and unmet needs) and needs predominantly unmet. Reasons cited by the latter two groups for why their needs had not been met included: limitations of the SAT (e.g. duration, format, scope, intensity and flexibility of support), ineffective/inaccessible interventions, and waiting times (Beresford et al., 2020). Individuals in either the needs predominantly met or mixed experience group generally

spoke highly of the psychoeducation programme which included content such as how autism affects people, the positive aspects of autism, and learning coping strategies for sensory-overload and anxiety (Beresford et al., 2020). Beresford et al. (2020) argued that for many, this programme impacted the way they saw themselves (resulting in them being more accepting and forgiving).

In relation to meeting individuals' needs, receiving individualised care was found to affect service users' experiences. All interviewees in the needs met group who required support following diagnosis reported having received individualised managed care that was co-ordinated by a single member of the team who acted as a named contact for the service user. Beresford et al. (2020) found this model of care to be very valuable to service users, with individuals who did not receive individualised care reporting at least some unmet support needs. Another factor found by Beresford et al. (2020) to influence whether or not individuals' needs were met was the way in which service users were referred to other support services/agencies. Some participants reported SATs supporting them to complete referrals where others were just signposted; this impacted whether an individual's needs were met as little evidence found signposting to be efficacious (Beresford et al., 2020).

Tint and Weiss (2017) specifically explored the service experiences of adult women with ASD, and identified 'Masking service needs' as one of three primary themes in their research. Within the theme of 'Masking service needs', four subthemes were identified: (1) Not looking the part, (2) Seeing is believing, (3) Hidden hurt of maintaining the mask, and (4) Unworthy of services. *Not looking the part* reflected the idea that there appeared to be a disconnect between how the woman with autism presented and others' preconceptions of ASD (including healthcare professionals' preconceptions). *Seeing is believing* related to service providers' tendency to minimise the needs of this population due to their masking abilities. The subtheme *Hidden hurt of maintaining the mask* conveyed the emotional and physical consequences of masking, due to the energy it required of the individuals. The final subtheme, *unworthy of services*, related to the participants' feelings of shame resulting from them accessing help due to their seemingly unaffected presentation. The findings of Beresford et al. (2020) suggest that services may not be able to fully identify the needs of women with autism, and therefore would be unable to fully meet their needs.

3.5.1.2 Barriers and Accommodations

Nicolaidis et al. (2013) contend that clinicians need to have an awareness of the healthcare disparities experienced by adults with autism and should be open to making accommodations and adopting strategies that may improve their healthcare experience. Examples of accommodations provided by Nicolaidis et al. (2013) included: offering patients an alternative waiting room, using precise language, and allowing extra time for patients to process information.

Saqr et al. (2017) used a mixed-method approach to learn about the needs of adolescents and adults with ASD within primary care settings. Retrospective chart reviews and a focus group were undertaken. The clinic involved in this study employed a pre-visit telephone assessment which allowed them to pre-plan individualised accommodations which could help overcome patients' barriers to care. The retrospective chart reviews identified documented changes that had been made to a standard clinic visit where barriers had been identified during the pre-visit telephone assessments. Of the charts reviewed to investigate the barriers/accommodations made (n=74), 23% (n=17) of patients had documented changes to their clinic visit (Saqr et al., 2017). Specific needs and barriers that were identified through the chart reviews included: difficulty with the waiting room/waiting (n=12), dislike of certain noises/loud noises (n=11), dislike of needles (n=6), difficulty being touched (n=6), history of aggression in medical facilities (n=3), dislike of bright lights (n=2) and being unable to tolerate assessment of vital signs (n=1) (Saqr et al., 2017). Where concerns were identified, individualised interventions were planned to assist patients to have a successful appointment. Examples of interventions undertaken by the clinic included taking the patient straight to the exam room (instead of having to wait in the waiting room), not taking vital signs, allowing the patient to wait in the car until the physician was ready to see the patient, not having the lights on in the exam room, and allowing the patient to have the first appointment of a session (Saqr et al., 2017).

The second part of the study by Saqr et al. (2017) involved conducting a focus group of 10 adults with ASD (9 male and 1 female), whereby participants discussed their clinic experiences and explored ways in which to overcome challenges and address unmet needs. Participants identified the three most stressful/problematic stages of clinic visits: (1) communicating with the clinician, (2) the physical exam, and (3) the

waiting room experience. Participants also identified the three main difficulties they experienced during a clinic visit which included: (1) sensory sensitivities, (2) anxiety caused by waiting, and (3) a lack of mutual understanding, communication and trust. Saqr et al. (2017) suggested accommodations to help alleviate the difficulties experienced by this population; these included controlling environmental conditions, use of distraction and tailoring communication between the patient and provider to the patient's needs, comfort and ability.

Participants' experiences of diagnostic assessment for ASD was investigated by Beresford et al. (2020). Overall, participants reported being satisfied with the way the assessment was managed but many found the assessment itself made them feel uneasy and anxious. Beresford et al. (2020) found sources of anxiety for service users to include: being the centre of attention, admitting to struggling at things that might be generally considered straightforward tasks, the use of open-ended questions, describing private matters and having more than one assessor. However, following a diagnosis of autism, many reported feeling a sense of relief with a short-term outcome being that the diagnosis allowed the individual to obtain access to support they were not previously entitled to (Beresford et al., 2020).

In relation to then accessing intervention(s) following diagnosis, some of the participants reported feeling unable to attend group intervention, and that alternative one-to-one sessions were not always available. Beresford et al. (2020) found a lack of an alternative to group sessions to be frequently cited as a reason for unmet need. Examples of reasons reported for not wanting to attend a group included: social anxiety, lacking confidence, and finding groups emotionally draining or distressing (Beresford et al., 2020). Two interviewees discussed support that had been provided to facilitate them attending group-delivered intervention which included a pre-meeting with the group facilitator, having the opportunity to view/be reassured about the venue, and allowing participation in the group via written means (Beresford et al., 2020). Additionally, some participants reported long delays between being offered support and the relevant group starting; a lack of contact from the SAT whilst waiting for the group intervention to start caused some interviewees anxiety (as they feared they had been forgotten). Practical barriers to accessing support were also discussed including public transport, journey times being too long, and the fact that sessions were only run during working hours (disadvantaging those in employment) (Beresford et al., 2020).

Relevant to individuals' ability to access services, Tint and Weiss (2017) identified *Accessing appropriate services: "a constant struggle"* as a theme in their research. This theme encompassed the challenges participants faced when trying to access services they required. Within this theme are five subthemes: (1) Not fitting the bill, (2) "A broken system", (3) Getting there is half the battle, (4) Square peg in a round hole, and (5) Looking outside the box for social support. Many women discussed being ineligible for support due either to diagnostic exclusionary criteria or due to their age, as many services are only available for children (*Not fitting the bill*). Another acknowledgement by participants was that many services are reactive rather than preventative in nature, which was labelled as *a broken system*. Participants additionally argued that *getting there is half the battle* in relation to accessing support. Participants reported lack of transportation as a barrier, with many participants unable to use public transportation due to fears of getting lost and/or sensory sensitivities. Additionally, difficulties locating appropriate services and dealing with associated paperwork impacted the accessibility of services to women with ASD. The subtheme, *a square peg in a round hole* stressed the need for individualised support with participants discussing times when mental health professionals had not made accommodations to their approach to help meet the needs of women with ASD. The final subtheme *looking outside the box for social support*, conveyed that many women in the study sought support from self-advocacy and support groups, both online and in-person when more formal services were unavailable. When specifically discussing their mental health, the women in this study reported prominent unmet mental health needs, with many women unable to access preventative services in a service system that is crisis-driven. Tint and Weiss (2017) highlight some of the challenges experienced by women with ASD when they are trying to access/receive appropriate service support.

3.5.1.3 Communication

Relevant to the experiences of adults with autism, Nicolaidis et al. (2013) found that adults on the autism spectrum had lower scores for patient-provider communication and general healthcare self-efficacy compared to adults not on the spectrum. 'Communication with clinicians' and 'availability of information' was discussed by Barber (2017) in relation to service delivery for adults with autism. When communicating with clinicians all three participants agreed that they did not value

being “preached to” by healthcare professionals (Barber, 2017, p.424). Additionally, according to Barber (2017), individuals with autism need information to be communicated to them in relation to what to expect when accessing healthcare services such as wards, GP practices and community services.

Communication was also explored by Saqr et al. (2017) who discussed the idea of a negative feedback loop that results in social interaction difficulties, which affects an individual’s ability to interact with a healthcare professional (for visual depiction, see Appendix 3). However, it is important to reaffirm here that communication is a two-way process, and that the role of the clinician in this negative feedback loop has not been considered by Saqr et al. (2017). The adults with autism who participated in the focus group shared that they experience anticipation prior to attending an appointment, which is linked to their fear of social interaction, and this generates anxiety (Saqr et al., 2017). This fear and feelings of anxiety can result in heightened sensitivities (e.g. sound, lights and touch) which can result in overstimulation that can make it almost impossible for the individual to successfully socially interact (Saqr et al., 2017). Inevitably this would negatively impact the individual’s experience of an appointment.

‘(Mis)Communication with service providers’ was identified as a primary theme by Tint and Weiss (2017) when exploring service experiences. The theme ‘(Mis)Communication with service providers’ contained three subthemes: (1) Not speaking the same service language, (2) (In)Experienced experts, and (3) Feeling heard. The subtheme *Not speaking the same service language* related to difficulties individuals experienced relating to processing speed limitations and how that was further affected by medical professionals’ time constraints. Additionally, many participants described difficulties with trying to communicate their sensory sensitivities to service providers. Participants often attributed the difficulties they experience communicating to *(In)Experienced experts*, stating service providers not only lacked experience of working with individuals with ASD but also lacked awareness of the impact of ASD on an individual. A minority of participants discussed positive interactions with providers, usually those who had experience of working with the ASD population. Participants valued being listened to by providers and appreciated *feeling heard* when service providers were willing to listen.

3.5.1.4 Professionals' Knowledge of Autism

One of the implications for service delivery discussed by Barber (2017) centred around health professionals' awareness and understanding of autism. One participant considered there to be a lack of awareness of autism amongst clinicians, with another participant stating "I believe that without such an awareness and understanding they would not be able to fully meet my health needs" (Barber, 2017, p.422) (Barber, 2017). Additionally, Tint and Weiss (2017) reported that service providers' knowledge and attitudes were frequently cited as barriers to effective care. Barber (2017) contends that active participation in autism awareness training courses should be made mandatory in order to provide appropriate services.

The study by Beresford et al. (2020) asked participants about the nature of the SATs, with participants often referring to SATs as having autism-friendly practices, evidencing the specialised nature of the service. A number of participants stated they felt understood, and viewed the staff as having expertise in autism (Beresford et al., 2020). Participants stated that utilising a service that understood its users provided them with emotional support in itself (Beresford et al., 2020). This finding by Beresford et al. (2020) highlights the importance that having expertise in autism has in delivering services that meet service user's needs.

3.5.1.5 Category 1 Summary and Critique

The five papers discussed above explored the service experiences and needs of individuals with autism. Key findings that were prevalent in the majority of papers in this category include: the importance of patient-provider communication, the presence of barriers to healthcare and a need for accommodations/individualised support. The impact of sensory sensitivities on accessing healthcare was also frequently discussed. A lack of knowledge/awareness/understanding of autism amongst healthcare professionals was prevalent in all papers except for Beresford et al. (2020) who found the professionals working in the SATs had expertise in autism which resulted in service users feeling understood and supported. This finding implies that healthcare professionals who have a good knowledge of autism can provide more appropriate support for service users. This is supported by Barber (2017) who contended that autism awareness training should be mandatory in order to provide services suitable for individuals on the spectrum.

The findings above need to be considered in the context of their strengths and limitations which will now be discussed. In contrast to all the other papers in this category, Nicolaidis et al. (2013) utilised a quantitative approach to explore healthcare experiences of individuals with autism, and then compared those findings to a control sample using an online survey. A total of 437 participants completed the survey: 209 adults with autism (59% female) and 228 without autism (66% female). A strength of this study is that it highlighted the existence of healthcare disparities when comparing adults with and without autism; this is an important finding. Additionally, this study used a community-based participatory research (CBPR) approach which facilitated the inclusion of adults with autism as both members of the research team and as participants in the research. However, this study does have limitations, which include: an unrepresentative gender bias, autism diagnoses not being independently confirmed, use of a convenience sample (affecting representativeness and generalisability), and that causal inferences cannot be drawn.

The second paper, Barber (2017), discussed current knowledge of healthcare needs whilst incorporating the experiences of three adults with Asperger's Syndrome. The importance of capturing the views of this population and the need to act upon their experiences in order to provide necessary services is stressed (Barber, 2017). A limitation of this article is that it is a non-empirical paper, but it does still incorporate the views of three experts by experience which is valuable. Due to the fact that only three individuals' experiences were captured by Barber (2017), the findings lack generalisability. However, although the sample size may be considered a limitation of the findings, an asset of the paper is that it gave a voice to service users on the spectrum with the hope of improving healthcare experiences for this population. Another strength of the paper is that it provided suggested accommodations professionals can make to their practice to improve healthcare service experience, whilst still emphasising that 'the one size fits all' approach is not appropriate when working with this population.

In contrast to the other papers, Tint and Weiss (2017) investigated the service experiences, unmet needs and barriers to care of only women with autism through the undertaking of focus groups. Therefore, their findings may not be applicable to men with autism. Within their sample, most of the women were white, had been diagnosed with autism in adulthood, and were not reporting a co-existing learning disability. This

could impact on the generalisability of their findings to all women with autism, including those from ethnic minorities, those who were diagnosed with autism as children and those who have a co-existing learning disability. Their study included experiences from a variety of services, including healthcare experiences. Additionally, the study was reliant on women's self-reporting of an ASD diagnosis, and therefore ASD diagnosis was not independently confirmed. Whilst this study does have limitations, it also has strengths, including the in-depth exploration of service experiences of women with autism using qualitative methods, as well as the fact that 20 women were included in the study to capture a range of service experiences.

The fourth study by Saqr et al. (2017) utilised a mixed-methods approach consisting of a retrospective chart review and focus group. A contribution of this study is the proposition that offering patients a pre-visit telephone assessment could allow healthcare facilities to identify service users' barriers to care and this could facilitate the pre-planning of individualised accommodations to help overcome these barriers. The authors acknowledge that pre-visit telephone assessments may not be possible in all medical settings, but that it can help patients overcome barriers to care and improve care for adults with autism. In addition, the authors captured the patients' experience of a medical setting through the undertaking of a focus group, with the focus group allowing participants to explore ways of overcoming challenges and unmet needs. This research, however, is subject to some limitations. Firstly, the sample size for the focus group is reported as being relatively small (10 adults) and mostly male (9 men), with only patients who could attend independently and communicate in a group setting able to engage with the focus group. This means that the focus group findings cannot fully represent the breadth of experiences of adult patients with autism. Secondly, even though the electronic records of pre-visit assessments and clinical visits were standardised, there are limitations of analysing data that has been collected by retrospective chart review. Examples of limitations of retrospective chart reviews include: incomplete, inaccurate or illegible documentation, missing charts, lack of a clear procedure for abstracting data and how to deal with incomplete data, and variance in the quality and/or location of the recorded information (Wickson-Griffiths et al., 2014)

The final paper in this category, Beresford et al. (2020), aimed to explore the experience of adults with autism of using Specialist Autism Teams (SATs) through

semi-structured interviews. Twenty-nine individuals were recruited from 9 research sites across England approximately 12 months after their first full assessment appointment. Purposive sampling was employed with the aim of ensuring representation of age and gender. A contribution of this study is that it highlighted factors that impacted the service users' satisfaction of services. The implications of this are that factors that negatively impact satisfaction can be acknowledged by services and then hopefully changes can be made. Strengths of this study were that it was the first to investigate SATs' provision in England, it included a project advisory group consisting of adults with autism, and the study contributed to the limited literature available on services specifically for individuals with autism. A limitation reported by Beresford et al. (2020) is the under-representation of service users from one of the research sites. Additionally, this study explored services designed specifically for individuals with autism and therefore the findings may not be applicable to services targeted for the general population or specific disabilities.

3.5.2 Category 2 – Exploration of factors at patient-, provider-, and system-level in healthcare

Two studies identified in this literature review specifically considered the healthcare experiences of adults with autism in the context of patient-, provider-, and system-level factors. When accessing services, there are factors to be considered within these levels. Both of the below studies examined factors which affected healthcare in the context of the three levels named above. Nicolaidis et al. (2015) discussed the interplay between the levels explored; they stated that the patient-level and provider-level interplay directly, with both levels being affected by the larger systems in which they are found (system-level). The first study, by Nicolaidis et al. (2015), utilised qualitative research methods to capture the healthcare experiences of adults with autism, whereas the second study by Bradshaw et al. (2019) reported a systematic review exploring barriers and facilitators to healthcare. The findings of Nicolaidis et al. (2015) and Bradshaw et al. (2019) will be discussed with consistent findings being highlighted.

3.5.2.1 Communication

Nicolaidis et al. (2015) identified three patient-level autism related factors relevant to communication: verbal communication skills, atypical non-verbal communication and

slow processing speed. The importance of using accessible language was discussed by Nicolaidis et al. (2015), with a failure to communicate in an accessible way associated with decreased patient autonomy. Providers' unwillingness to allow patients to communicate in writing was reported as a common reason why patients had experienced a negative healthcare interaction or had received poor care (Nicolaidis et al., 2015). The providers' willingness to consider accommodations (such as communicating via email, and successfully incorporating a supporter into the service user's sessions/care) improved healthcare interactions (Nicolaidis et al., 2015).

Communication issues were also identified as a patient-level factor by Bradshaw et al. (2019). The presence of patient-provider communication difficulties was prevalent in several of the studies within their review, with individuals having difficulties identifying their inner experiences and then communicating them to a professional for a variety of reasons (sensory sensitivities, unusual communication style, and limited time to process and respond to a professional) (Bradshaw et al., 2019). Bradshaw et al. (2019) reported anxiety as a patient-level factor that had a relationship with communication difficulties, i.e. communication difficulties can cause an individual with autism anxiety, but anxiety can also make communication difficulties worsen. Arranging appointments, fear of social interaction and the anticipation of attending clinics were provided as examples of anxiety-producing phenomenon (Bradshaw et al., 2019). It is important to acknowledge that an inability to effectively communicate with a professional can affect assessments which could possibly result in physical and mental health conditions being missed (Bradshaw et al., 2019).

Bradshaw et al. (2019) identified incorporating communication accommodations and supporters as a provider-level factor. This factor contends that adults with autism need flexibility in the way they communicate with health professionals. If accommodations are not given (e.g. allowing individuals to communicate in writing or through visual aids), communication barriers may arise (Bradshaw et al., 2019). In agreement with Nicolaidis et al. (2015), Bradshaw et al. (2019) emphasised the importance of incorporating supporters, but maintained the professional should communicate directly with the patient when possible.

3.5.2.2 Lack of autism knowledge

Both adults with autism and their supporters criticised providers' lack of knowledge about autism in adults (Nicolaidis et al., 2015). Bradshaw et al. (2019) found a lack of provider knowledge and training to be a provider-level factor in their review. Additionally, supporters reported that they were frequently required to have to teach providers about autism (Nicolaidis et al., 2015). Providers' incorrect assumptions about patients' skills or needs were cited as a common explanation as to why participants had felt they had received poor care or had a negative healthcare experience (Nicolaidis et al., 2015). Additionally, some participants reported being concerned that providers would hold misconceptions or believe myths about autism (Nicolaidis et al., 2015).

The majority of participants in the study conducted by Nicolaidis et al. (2015) asked for increased training for providers on autism and more patient resources/information to improve health experiences. A conclusion of Nicolaidis et al. (2015) was that the patients' healthcare experience largely depended on providers' knowledge, skill, attitudes and behaviours in working with individuals on the spectrum (areas in which training was recommended). Bradshaw et al. (2019) argued that lacking knowledge, training and confidence in autism can result in barriers to accessing appropriate healthcare for this population, with autism being missed in adults. Alike Nicolaidis et al. (2015), the authors advocate for autism training and awareness raising to improve the healthcare experience for adults with autism (Bradshaw et al., 2019).

3.5.2.3 Accessibility of support

At the systems level, Nicolaidis et al. (2015) discussed the complexities of the healthcare system and the availability of support. It was highlighted that many positive healthcare experiences discussed in their study had required assistance, either from a family member or disability services professional (Nicolaidis et al., 2015). Accessibility of facilities was found to impact service experience; over-stimulating waiting rooms resulted in negative experiences with quiet offices, natural lighting and private waiting rooms leading to positive experiences (Nicolaidis et al., 2015).

Sensory issues/differences were identified as a patient-level, autism-related factor that impacted upon healthcare interactions by both Nicolaidis et al. (2015) and Bradshaw et al. (2019). Sensory sensitivities can cause distress when attending healthcare

appointments; additionally, having to take public transport to attend an appointment, the healthcare environment (e.g. lighting, proximity to people, disorientation) and examinations can result in sensory discomfort (Bradshaw et al., 2019). Bradshaw et al. (2019) acknowledged that anxiety can have a negative effect on sensory sensitivities whereby anxiety can make sensory sensitivities worse, but that sensory sensitivities can also heighten anxiety.

In relation to accessibility of services, Bradshaw et al. (2019) identified two system-level factors: accessibility of healthcare facilities and limited referral pathways. Accessibility of healthcare facilities stresses the importance of creating a calm clinical environment for the individual; this can be done by restricting sensory stimulation by making changes to healthcare environments (e.g. natural lighting, calm décor and private waiting rooms where possible) and minimising time spent in waiting rooms which results in stress, anxiety and discomfort (Bradshaw et al., 2019). Limited services and referral pathways have also been found to affect the care experiences of both adults with autism and healthcare professionals. Limited resources, growing caseloads, delays between referral and diagnosis, waiting lists and lack of clear pathways are examples of reported barriers (Bradshaw et al., 2019).

3.5.2.4 Additional factors

Additional patient-level, autism-related factors highlighted by Nicolaidis et al. (2015) were a need for consistency and challenges with organisation. Nicolaidis et al. (2015) found the providers' willingness to consider accommodations (such as providing photographs of staff members in advance and detailing what the process would be like) improved healthcare interactions. The final patient-level factor identified by Bradshaw et al. (2019) was previous experiences with health professionals which reflected the finding that previous negative experiences in healthcare can be seen as a significant barrier to obtaining effective care. This finding highlights the importance of having successful healthcare interactions with adults with autism as negative experiences can later become a barrier to care/services.

In addition, participants found stigma to be present in healthcare; some participants reported feeling reluctant to share their diagnosis due to fear of discrimination (Nicolaidis et al., 2015). Societal issues, such as poverty, were acknowledged to impact healthcare too (Nicolaidis et al., 2015). Poverty was also acknowledged as a

socio-economic factor by Bradshaw et al. (2019) as well as health, unemployment and educational attainment.

3.5.2.5 Category 2 Summary and Critique

Both Nicolaidis et al. (2015) and Bradshaw et al. (2019) explored factors that affected the healthcare experiences for this population at the patient-, provider-, and system-levels. Considering factors that affect healthcare experiences within levels allows the factors to be considered in the context of their relevant interaction; for example, the factor may appear in interactions between the service user and professional or may be a consequence of the larger system such as the way healthcare is delivered. Key findings discussed within this category include: the prevalence of communication challenges, a lack of autism knowledge in healthcare providers, and difficulties related to accessing support. Additionally, sensory issues experienced by service users and the need for accommodations were discussed in relation to communication and accessibility of support. Both articles highlighted the need to make environments friendly for individuals with autism by limiting sensory stimulation. Autism training for healthcare professionals was promoted by both Nicolaidis et al. (2015) and Bradshaw et al. (2019). Through exploring factors at various levels, numerous ways to help services overcome healthcare inequalities for this population can be recommended. The contributions and limitations of the papers discussed above will now be discussed.

Nicolaidis et al. (2015) aimed to capture the healthcare experiences of adults with autism and provide recommendations for improving care. There was a total of 55 participants in this study, 39 adults with autism and 16 individuals who had experience of supporting adults with autism in healthcare environments (Nicolaidis et al., 2015). Similar to Nicolaidis et al. (2013), this study utilised a CBPR approach which allowed rich, qualitative data to be acquired. A variety of interview modes were available to participants (telephone, instant messenger, email, or in-person) to allow as diverse as possible a sample to be involved. The inclusion of supporters to this study as a secondary sample allowed healthcare issues experienced by individuals unable to participate in the study to be captured. This study obtained participants' recommendations for improving care; however, it's important to acknowledge that the recommendations obtained were specific to certain participant's needs, and this highlights the need for individualised accommodations. Nicolaidis et al. (2015)

contended that healthcare systems need to discover ways to make healthcare services/facilities more accessible to adults with autism. Limitations of this study identified by Nicolaidis et al. (2015) include that it lacks generalisability and the sample was predominantly non-Latino, white, and from the US. However, this study aimed to prioritise obtaining depth of understanding and rich data over generalisability.

The second paper in this category, Bradshaw et al. (2019), undertook a systematic review exploring the barriers and facilitators to healthcare for adults with autism. The undertaking of a systematic review allows the results of multiple studies in the field to be collated and summarised, thereby making the available evidence more accessible. Systematic reviews are a valuable resource as they limit bias, improve the generalisability and consistency of findings and help draw accurate and reliable conclusions (Gopalakrishnan and Ganeshkumar, 2013). However, systematic reviews do have their flaws. For example, systematic reviews cannot address problems that were present in the design and undertaking of the primary studies. Although some systematic reviews comment on the limitations of papers contained within their review, Bradshaw et al. (2019) did not. Additionally, the systematic review undertaken by Bradshaw et al. (2019) only included four online databases and therefore additional relevant research articles may have been missed. Furthermore, although the way the literature search was undertaken was discussed, the way the screening was undertaken was not shared in great detail (e.g. an inclusion and exclusion table was not provided). This review contributes to the existing literature by identifying ways in which the healthcare needs of adults with autism can be better met at the patient-, provider-, and system-level by considered barriers and facilitators to healthcare for this population.

3.5.3 Category 3 – Barriers to healthcare

Three studies fall within this category: Dern and Sappok (2016), Vogan et al. (2017) and Raymaker et al. (2017). Dern and Sappok (2016) used a qualitative approach whereas the other two studies were quantitative in nature. The findings of the above mentioned studies will now be discussed.

3.5.3.1 Quantifying barriers to healthcare

Vogan et al. (2017) explored barriers to service use for adults with ASD. In relation to barriers, approximately three-quarters of participants indicated they had a need for

services that they could not access (Vogan et al., 2017). When asked about barriers they had experienced, a mean of 4.7 barriers were reported (range from 0 to 10) with over three quarters of participants reporting they had experienced three or more barriers to service use (Vogan et al., 2017). Not knowing where to find help (66%), feeling overwhelmed with the steps to seek help (53%), having difficulties describing problems and needs (47%), and negative experiences with professional help (47%) were the four most commonly reported barriers experienced by the participants (Vogan et al., 2017).

In order to explore whether people with autism experience more barriers in healthcare compared to other populations, Raymaker et al. (2017) compared healthcare barriers experienced by adults with autism to adults with and without other disabilities. To do this, they adapted a measure already in existence that assessed barriers to services and made it more applicable to individuals with autism. The findings of Raymaker et al. (2017) indicated that individuals with neither a disability nor autism experienced far fewer barriers to healthcare than the other two groups in the study. Within this group, only 10 items were reported by 5% or more of the group population (Raymaker et al., 2017). The group of participants with disabilities, but without autism, were found to endorse considerably more items than the group with neither disability nor autism, with 34 barriers being endorsed by 5% or more of the population (Raymaker et al., 2017). The group of adults with autism (without disability) showed a different trend compared to the two other groups. In this group, 56 barriers were reported by at least 5% of the population (Raymaker et al., 2017). In pairwise comparisons between the autism group and the other two groups, statistically significant differences were found, with higher proportions found in the autism group (Raymaker et al., 2017). These findings highlight that individuals with autism experience more barriers to healthcare than individuals without autism, but also compared to individuals with other disabilities.

3.5.3.2 Categorising barriers

Dern and Sappok (2016) established numerous difficulties that individuals with autism may encounter when accessing healthcare and grouped them into the following categories: (1) Making appointments, (2) Waiting area, (3) Examination, (4) Communication, (5) Hospital, and (6) Sensory issues. Strategies to overcome/help ease the difficulties were also grouped into the same categories. In relation to making

appointments, an adult with autism may find it difficult to make appointments over the phone; allowing appointments to be arranged via email could be a suggested strategy to overcome this difficulty. Identified barriers related to the waiting room included: physical closeness to other patients, stress due to uncertainty, and sensory overstimulation. Strategies to reduce these barriers include: allocating patients with autism to the earliest or latest time slots, trying to minimise waiting periods, and offering a separate waiting room/allowing patients to wait outside or in the car until their appointment. Examples of barriers relating to communication included: a lack of time to think/respond, difficulties in communication, literal understanding of language and stress due to open questions. Suggested recommendations to healthcare professionals to ease stress related to communication included: giving patients enough time to answer, the use of simple and exact language and avoidance of open questions. In relation to sensory issues, difficulties and fear of sensory overload can be eased by using low-stimuli environments and avoidance of disturbing noises such as phones and sirens.

In relation to types of barriers, Raymaker et al. (2017) found items related to patient-provider communication to be most endorsed in the autism group in their study; over a third reported not being able to process information quickly enough to participate in real-time interactions about healthcare, with just under a third reporting difficulties communicating with healthcare providers/staff (Raymaker et al., 2017). In their study, in both the autism and disability groups, more individuals endorsed that appointments were too short to accommodate communication needs, compared to individuals without autism or a disability (Raymaker et al., 2017). Sensory distress was reported by a third of participants with autism, with the impact of sensory distress on communication and capacity to tolerate exams/tests endorsed by a quarter of participants with autism (Raymaker et al., 2017). These percentages were found to be significantly higher compared to the other two populations in their study. Additionally, individuals with autism experienced greater barriers to healthcare in relation to emotional regulation and healthcare navigation (Raymaker et al., 2017).

3.5.3.3 Barriers impacting on service delivery

The difficulties identified by Dern and Sappok (2016) indicate a significant problem in how services are delivered to adults on the spectrum. Dern and Sappok (2016)

proposed that by making accommodations professionals can make consultations easier for individuals with autism. It is proposed by Dern and Sappok (2016) that knowledge about the particular needs of individuals on the spectrum needs to be improved amongst healthcare professionals, and suggested that autism training could be added to the pre-qualification curriculum for healthcare professionals such as GPs and nurses.

Vogan et al. (2017) explored service satisfaction in healthcare for adults with ASD and found that adults with ASD and mental health problems were significantly less satisfied with services than those without mental health difficulties (Vogan et al., 2017). Vogan et al. (2017) found dissatisfaction to be associated with increased distress at a later time period. Healthcare providers need to consider this as it may be possible to reduce the distress experienced by individuals by improving their satisfaction with healthcare services.

3.5.3.4 Category 3 Summary and Critique

The studies contained within this category, Dern and Sappok (2016), Vogan et al. (2017) and Raymaker et al. (2017), highlight the barriers faced by adults with autism in relation to accessing healthcare services. Findings that were discussed within this category included: the prevalence of barriers to healthcare for individuals with autism, a comparison of barriers experienced for individuals with autism and other groups, and a discussion of the different types of barriers and how barriers can impact on service delivery. The contributions and limitations of the studies within this category will now be deliberated.

Dern and Sappok (2016) explored barriers and facilitators in healthcare through discussions at a series of meetings with both individuals with autism and autism professionals in attendance. This study contributes to the literature by identifying barriers to healthcare for adults with autism, suggesting accommodations for healthcare professionals, and identifying helpful resources to facilitate access to healthcare for individuals with autism. Individuals who were unable to attend the meeting were invited to share their experiences in an online discussion board. A strength of this study is the amalgamation of perspectives from both adults with autism and professionals working in the field of autism. An additional strength was the opportunity for online participation for individuals who may not have felt able to attend

the meetings in person. A criticism of the research article is that the number of adults with autism and professionals involved in the study has not been included. Additionally, whether ethical approval and/or consent was required for this project was not disclosed.

The second paper, Vogan et al. (2017), aimed to capture: the experiences of adults with ASD in accessing and using healthcare services, barriers to service use, and unmet service needs. This study involved questionnaires being completed by 40 adults with autism (aged 18-61 years) every two months over a period of 12 to 18 months. Participants included those with a diagnosis of either Asperger Syndrome or ASD without learning disability. Autism diagnosis was confirmed using an ASD self-report screening tool. To increase accessibility of the questionnaire to participants, participants had the option of completing the questionnaire on paper, over the phone or online. Thirty-nine participants completed the questionnaire online, with one completing the questionnaire by phone. In this study, 87.5% of the participants were white, 45% were female, and the mean age of the sample was 35.88 years (Vogan et al., 2017). The findings of Vogan et al. (2017) found participants to be somewhat satisfied with the services they received, but found that adults with autism come across numerous barriers in accessing the services. A limitation of this study is that given that the majority of individuals completed the questionnaire online and had high income, the findings may not be generalisable to those who do not have internet access or those with lower incomes (Vogan et al., 2017). An additional criticism is that questionnaires require self-report which is then reliant on memory; therefore, there is no guarantee that the data obtained is definitely accurate (Vogan et al., 2017). Additionally, forty-five percent of the sample were female which does not reflect the gender ratio prevalent in autism (Vogan et al., 2017). It is important to acknowledge that the findings may not be generalisable; within their sample, eighty percent of the sample reported using some form of mental health or behavioural care, and three-quarters of participants indicated they had a mental health problem (Vogan et al., 2017). This might mean that the findings of this study might not be applicable to individuals with autism but without mental health difficulties. A strength of the study was the way that barriers to services could be captured in a quantitative format, which allowed barriers to services to be quantified (Vogan et al., 2017).

The final paper in this category, Raymaker et al. (2017), used a CBPR approach with the aim of identifying and comparing healthcare barriers experienced by adults with autism compared to adults with and without other disabilities. This study included 437 participants divided into the following three groups in order to make comparisons: adults with autism (N = 209), adults with disabilities but without autism (N = 55), and adults without autism or disabilities (N = 173) (Raymaker et al., 2017). Participants were US residents, aged 18 years or over. The mean age of participants was 40 years, with the majority of participants being non-Hispanic females. The instrument/questionnaire was distributed to participants via email. Raymaker et al. (2017) compared the healthcare barriers experienced by individuals with autism, individuals with disabilities, and individuals without autism or a disability. A strength of this study, relevant to this literature review, is that it highlighted the barriers individuals with autism face in healthcare. Another strength of this study is the development of an instrument that can be used in healthcare settings to assist the assessment of needs of individuals with autism (Raymaker et al., 2017). Limitations to the generalisability of these results is the self-report nature of the data, the utilisation of convenience sampling, and that only those who had internet access and those who could complete an online survey (either alone or with support) could take part. An additional limitation of the study was that the disability group had a smaller N compared to the other two groups in the barriers comparison. This study contributes to the literature by demonstrating that individuals with autism experience greater barriers to healthcare than individuals with other disabilities, and those without disability. Through identifying barriers for this population, strategies can be implemented to try and overcome them.

3.5.4 Category 4 – Experiences of mental health support

This category contains three articles which specifically focus on the experience of individuals with autism of accessing mental health support. The first study in this category, Crane et al. (2018), explored the experiences of young adults with ASD and mental health problems, and the support they sought for them. Camm-Crosbie et al. (2018) explored the experiences of treatment and support for mental health problems, self-injury and suicidality in adults with autism. The third paper by Maddox et al. (2019) aimed to identify ways to improve community mental health services for adults with autism for the treatment of their co-existing mental health difficulties. Whilst the research by Crane et al. (2018) had many components, this literature review will focus

specifically on findings relevant to this review, e.g. participants' experience of mental health services. The findings of the above mentioned studies will now be discussed.

3.5.4.1 Prevalence of mental health difficulties and seeking support

Of the 109 individuals who completed the online questionnaire in the study by Crane et al. (2018), 88 (80.7%) reported that they had experienced mental health problems, either currently or previously. In relation to seeking support, Crane et al. (2018) found that 73 (90.1%) respondents reported having sought support for mental health difficulties from clinical/healthcare professionals. It was found by Camm-Crosbie et al. (2018) that 90.4% of the 200 respondents in their study had a mental health diagnosis, with depression and anxiety being the most prevalent. In regards to seeking treatment for mental health, self-injury and suicidality, Camm-Crosbie et al. (2018) (N = 197) found that 164 were currently receiving/had previously received treatment, 29 needed/currently needed treatment but had not received any, and 4 participants did not require treatment.

3.5.4.2 Satisfaction with support received

Overall, Crane et al. (2018) found interviewees were generally dissatisfied with the standard of the support they received. Relevant to satisfaction, Camm-Crosbie et al. (2018) identified a theme titled 'wellbeing' which covered both negative and positive impacts to wellbeing. Inappropriate support, absence of treatment and feeling excluded from society were examples of factors that negatively impacted participants' wellbeing. On the other hand, receiving appropriate treatment and support was found to positively impact wellbeing. Crane et al. (2018) specifically enquired about the usefulness of support and how comfortable participants were sharing difficulties with professionals. When asked how useful participants found the support offered by clinical/healthcare professionals (N = 73), only five (6.8%) found the support extremely helpful, with 12 (16.4%) finding it very useful (Crane et al, 2018). Conversely, 17 (23.3%) respondents reported finding the support not at all useful, with 20 (27.4%) reporting the support to be a little useful (Crane et al., 2018). In relation to feeling comfortable with sharing their mental health difficulties with professionals, Crane et al. (2018) found that only 3 (4.1%) respondents felt extremely comfortable to do so. The majority of respondents reported feeling only 'a little' comfortable to share their mental health difficulties with their healthcare professional (N = 24, 32.9%) (Crane et al.,

2018). Crane et al. (2018) proposed the idea that invisible illnesses are taken less seriously; they identified a theme titled 'Stigma' in their study that encompassed stigma from a variety of sources, such as society, professionals, as well as family and friends. Trust and respect were highlighted as desirable professional qualities by Crane et al. (2018).

3.5.4.3 Accessing support

In their study, Crane et al. (2018) found that few respondents reported feeling confident in knowing who to contact if they were experiencing mental health problems, with even fewer respondents feeling confident that if they did seek help, that they would get appropriate support. Camm-Crosbie et al. (2018) identified a theme in their work titled 'People like me don't get support' which highlights the difficulties individuals encounter when accessing appropriate treatment and support; for adults with autism and co-existing mental health difficulties, some participants felt they fell through a gap in the available services. Participants reported their need for services being dismissed as they were viewed as either coping, managing, or functioning. The participants contended that support is geared towards children with autism, with long waits and a lack of funding in adult services. In relation to support, 47.8% (76 participants) of adults who reported that they would like to receive support, received none (Camm-Crosbie et al, 2018).

The agency leaders who participated in the study by Maddox et al. (2019) believed that many adults with co-existing autism and mental health difficulties may not be aware of the treatment available to them. Maddox et al. (2019) also discussed a disconnect between mental health and developmental disability services, which can result in clients being turned away from mental health services. Clinicians and agency leaders both agreed that there is not a strong system in place for adults with autism and mental healthcare needs (Maddox et al., 2019).

3.5.4.4 Barriers and Facilitators

'Barriers to support', an identified theme by Crane et al. (2018), included barriers such as: a general lack of available services, delays in being able to access support (waiting lists), services not being tailored to individual need, a rush to discharge patients, lacking pathways between/within services, and the poor transition from Child and Adolescent Mental Health Services to Adult Mental Health Services. An additional

theme identified by Crane et al. (2018) was 'Relationships' which portrayed how family and friends were seen as a strong source of support which was required to compensate for the lack of professional support being received.

Client-related barriers to mental health services were identified by clinicians and agency leaders (Maddox et al., 2019). Professionals expressed concerns about the exhibition of challenging behaviour during the sessions with adults with autism. Additionally, clinicians acknowledged that the client's cognitive limitations can interfere with traditional therapies. It is argued by Maddox et al. (2019) that the barriers reported by clinicians may reflect their misperceptions about adults with autism (e.g. that all adults with autism exhibit challenging behaviour and cannot engage in talking therapies due to cognitive limitations).

In the study undertaken by Maddox et al. (2019), all three stakeholder groups uniformly wanted to improve community mental health services for adults with autism and co-existing mental health conditions. Ways to facilitate this were discussed that included: a need for clinician training, the use of clear and direct language, a need for structure and predictability in sessions, for clinicians to be comfortable with silences and slow pacing, for treatment to be individualised to the client, for sensory issues to be considered, for practical and present-focused therapeutic approaches to be utilised, and a need for clinicians to focus on treating the mental health condition (rather than trying to change an individuals' autistic traits) (Maddox et al., 2019). Crane et al. (2018) and Camm-Crosbie et al. (2018) also emphasised the need for support to be tailored to individuals' needs, with the concept of individually tailored treatment and support being both beneficial and desirable identified as the over-arching theme in the research of Camm-Crosbie et al. (2018).

3.5.4.5 Lack of knowledge

In Crane et al. (2018), interviewees expressed concerns that professionals may not have sufficient levels of expertise and knowledge of autism. Camm-Crosbie et al. (2018) identified lack of understanding and knowledge as a theme in their study, with this theme emerging from service users' negative experiences of professionals who had a very poor knowledge of autism. Many participants felt a need for professionals to be better trained in autism, with participants feeling it should not be their responsibility to teach professionals about autism (Camm-Crosbie et al., 2018). Many

participants reported feeling their symptoms had been disregarded by professionals, or that they had not been believed by professionals (Camm-Crosbie et al., 2018). Continuity of care was regarded highly by service users, due to the time it takes for service users to build rapport with professionals (Camm-Crosbie et al., 2018).

At the clinician-level, Maddox et al. (2019) reported that adults with autism believed clinicians: do not understand autism, do not give practical recommendations, do not challenge adults with autism to make progress, and do not accommodate the individuals' sensory differences. Clinician participants cited limited knowledge about autism as a barrier to treating adults on the spectrum, with both clinicians and agency leaders stating that limited knowledge of autism results in poor competence and low confidence in working with people who have autism (Maddox et al., 2019). The findings of Maddox et al. (2019) illustrate the need for clinician training in autism, both at a pre-qualification level and in continuing education. In addition to the lack of understanding reported in clinicians, Crane et al. (2018) identified a theme titled '(Not) understanding my normal' in which participants reported feeling unsure whether the difficulties they were experiencing were due to their autism or their mental health difficulties. This could highlight a need for psychoeducation in individuals with autism. Interviewees felt that any support provided needed to bridge the gap between autism and mental health (Crane et al., 2018).

3.5.4.6 Category 4 Summary and Critique

The articles discussed within this category, Crane et al. (2018), Camm-Crosbie et al. (2018), and Maddox et al. (2019), explored the experiences of adults with autism who accessed mental health support. In both Crane et al. (2018) and Camm-Crosbie et al. (2018), over four-fifths of participants reported experiencing mental health difficulties. Whilst many individuals sought treatment for their difficulties, Camm-Crosbie et al. (2018) found that 14.7% (N = 29) of their participants had needed/currently needed mental health treatment but had not/were not receiving it. Key findings which were evident throughout the articles included: a general dissatisfaction with mental health support for people with autism, the existence of barriers but also facilitators for people with autism when trying to access mental health services, the lack of knowledge/understanding/expertise amongst clinicians in autism, a need for tailored/individualised support for adults with autism, and a lack of services for adults

with autism with unclear pathways resulting in clients falling through the gaps of service provision. The need for clinician training was present again, with Maddox et al. (2019) advocating for training at both a pre-registration level and in continuing education. Two of the research studies discussed in this category were undertaken in the United Kingdom (UK) evidencing the burgeoning interest in the UK for improving mental health services for adults with autism.

The first paper in this category, Crane et al. (2018), adopted a CBPR approach to explore the mental health experiences of young adults with autism, and their perspectives on the support they sought/received for their mental health difficulties. A total of 130 participants took part in the study, either by completing an online questionnaire (N = 109) or by undertaking a semi-structured interview (N = 21). All participants had to have received a formal diagnosis of an autism spectrum condition, be aged 16 to 25 years, and be residing in England. This study contributes to current understanding by highlighting that support currently being provided by clinicians for mental health difficulties in adults with autism might not be meeting the needs of this population. The findings also showed that the majority of individuals did not feel comfortable sharing their mental health difficulties with professionals, which could prevent them from receiving appropriate support. Additionally, few participants were aware of who to contact if they were struggling and even fewer believed that they would receive appropriate support if they asked for help. The interviews added to these findings with participants reporting high levels of stigma, barriers to healthcare, and having to rely on family and friends for support. This study has a number of strengths including: the utilisation of a CBPR approach and mixed-methods design. Mixed method designs increase the meaningfulness and validity of constructs by counteracting method biases; using mixed methods designs allows quantitative and qualitative methods to be combined to explore both overlapping but also differing aspects of a phenomenon (Gray, 2018). Limitations of the study include a lack of ethnic diversity, the fact that there was no comparison group of individuals without autism, and that only individuals who were verbally/cognitively able participated meaning the results may not be generalisable to those with co-existing learning disabilities.

The second paper, Camm-Crosbie et al. (2018), aimed to explore the experiences of individuals with autism accessing treatment/support for mental health difficulties, self-injury and suicidality in the United Kingdom using an online questionnaire. A total of

200 adults (122 females, 77 males and 1 unreported) completed the questionnaire. Participants were aged between 18 years and 67 years, and did not have co-existing learning disability. Thematic analysis was undertaken on the open-ended questions in the online questionnaire; thematic analysis is a method that allows for the identification and analysis of themes within data, whilst also providing an interpretation of participants' meanings (Gray, 2018). A contribution of this study is the fact that it was the first study to explore the treatment/support experiences of adults with autism who have co-existing mental health difficulties (Camm-Crosbie et al., 2018). The results of this study have strong implications for services; the study highlights that there needs to be appropriate services available for this population that meets their needs, in order to prevent individuals falling through the gaps in services. Strengths of this study include: the participatory approach which ensured questions were relevant/clear to people with autism, and the online recruitment method which resulted in a large sample participating due to the accessible format (Camm-Crosbie et al., 2018). However, the findings of this study may not be generalisable to those who have co-existing learning disability or those who would have required support to participate. Additionally, the sample comprised mainly of women with autism which is the opposite of the gender bias prevalent in autism. Additionally, diagnoses were all self-reported and therefore the reliability cannot be confirmed.

The final study to be discussed in this category, Maddox et al. (2019), used qualitative methods to find ways of improving community mental health services for adults with autism seeking treatment for their co-existing mental health difficulties in the United States. They did this by identifying barriers and facilitators to mental healthcare (Maddox et al., 2019). Seventy-seven individuals participated in either a semi-structured interview or focus group (22 adults with autism who had experience of mental health services, 44 community mental health professionals, and 11 community mental health agency leaders). Of the 22 participants with autism, 21 had experience of mental health services as an adult. This qualitative study contributes to the literature by examining ways to improve the ability of community mental health teams to meet the mental health needs of adults with autism. However, this study does have limitations. These include: mental health agencies were not randomly selected to participate and this could impact generalisability, the sample of adults with autism may not be representative of the wider autism community, and the fact that participants had

to self-select to take part. Despite its limitations, the findings of this study can hopefully be used to increase access to mental health services for adults with autism. By exploring barriers at the clinician-, client-, and system-level, more opportunities for positive change could be clearly identified. The sharing of discussed facilitators can provide professionals/services with practical strategies to improve their practice with this patient group.

3.6 Overview of Literature Review 1 Findings

Overall, the literature indicates that adults with autism experience barriers in accessing healthcare services. Key themes which arose from the literature included: the healthcare needs of adults with autism, the importance of patient-provider communication, difficulties adults with autism have accessing support including the presence of barriers and facilitators to services (and need for accommodations), and a lack of autism knowledge amongst healthcare professionals (and a need for autism training). The need for individualised care, the existence of unclear pathways and challenges navigating services experienced by adults with autism, and the impact of sensory differences on an individual's ability to access healthcare were also discussed. Additionally, the prevalence of mental health difficulties in adults with autism, rates of mental health support, and satisfaction with support were explored.

The majority of articles within the literature review reported healthcare professionals' lack of knowledge/understanding/awareness of autism and how it affects/impacts adults with autism. However, none of the articles included in this literature review then went on to measure the autism knowledge of healthcare professionals. The next chapter in this thesis contains the Phase 2 Literature Review which will explore the existing literature surrounding the autism knowledge of healthcare professionals.

3.7 Chapter Summary

This chapter contained a literature review exploring the needs and experiences of adults with autism when accessing healthcare relevant to Phase 1 of the current study. This review was undertaken to establish the current level of understanding related to this topic, and the review findings were summarised, with critique provided. The

subsequent chapter contains a second literature review exploring healthcare professionals' level of ASD knowledge.

Chapter Four:
Healthcare Professionals' Knowledge of ASD

4.1 Introduction

The previous chapter contained a literature review exploring the needs and experiences of adults with autism in relation to their accessing of healthcare. This chapter will review and present the existing literature available on healthcare professionals' knowledge of ASD. Following this, the gap in the literature this study aims to address will be discussed.

4.2 Scope of Literature Review 2

Prior to the undertaking of this literature review, an initial search of Google Scholar using a mix of key words (such as 'ASD knowledge', 'ASD understanding', 'ASD awareness', 'mental health professionals', 'mental health services') was undertaken to identify relevant literature to the third research question of the current study:

What knowledge of ASD exists amongst mental health professionals working within Adult Mental Health Services? (Phase 2 Literature Review)

The initial search only identified one paper exploring the knowledge of ASD in mental health professionals in adult services. Due to this, the scope of the literature review was extended to explore the knowledge of ASD amongst any healthcare professional. Therefore, the second literature review in this thesis will present the current knowledge available to address the following research question:

What knowledge of ASD exists amongst healthcare professionals? (Phase 2 Literature Review)

The chapter will now provide the method utilised for the second literature review, followed by the literature review findings.

4.3 Method for Phase 2 Literature Review

4.3.1 Search Strategy

The same electronic databases that were utilised for the Phase 1 Literature Review were utilised for this literature review (Science Direct, CINAHL, MEDLINE, ProQuest Psychology, ProQuest Nursing & Allied Health, PsychInfo, ASSIA, and PubMed). ResearchGate and Google Scholar were also searched for pertinent articles. Review parameters required all articles to be: published between January 2013 and December 2020, available in English language, peer-reviewed and available to the researcher in full-text (via online means). The same rationale for obtaining papers written from 2013 onwards for Phase 1 applies to this phase (to ensure contemporary views of autism). The search terms and Boolean operators used for the literature searches are shown in Figure 4. Additional filters applied to each search term can be seen in Appendix 4.

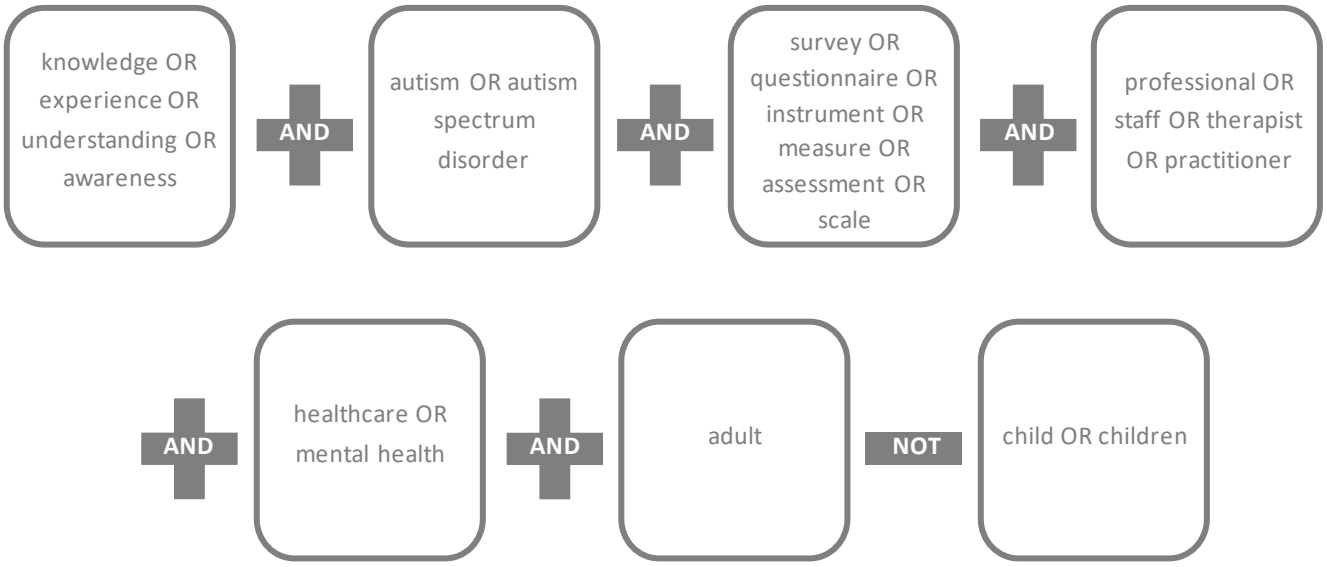

Figure 4: Search terms used for the literature search (Phase 2)

The literature search, using the search terms provided above, identified a total of 498 records. The number of identified records per database is provided in the table below (Table 5).

Table 5: Total number of records per database

Database	Total number of hits
Science Direct	15
CINAHL	7
MEDLINE	9
ProQuest Psychology	141
ProQuest Nursing and Allied Health	144
PsychInfo	23
ASSIA	111
PubMed	48
Total number of hits (all included databases)	**498**

Of the 498 articles retrieved, 248 were duplicates and were therefore removed, leaving 255 articles to be screened. ResearchGate and Google Scholar were also searched, however no additional articles were identified.

4.3.2 Inclusion and Exclusion Criteria

The below table (Table 6) details the inclusion and exclusion criteria that were applied to the screening of the 255 articles.

Table 6: Inclusion and exclusion criteria for literature search (Phase 2)

Inclusion Criteria	Exclusion Criteria
▪ Articles must include healthcare professionals ▪ Articles must explore knowledge of ASD in healthcare professionals ▪ Articles must be available in English ▪ Articles must be available as a full-text version through sources accessible online to the researcher	▪ Articles that are not specific to knowledge of ASD ▪ Articles that only measure professionals' knowledge of childhood autism ▪ Articles that solely evaluate interventions/ASD training programmes ▪ Articles that only include school practitioners ▪ Articles that explore views of autism rather than ASD knowledge

4.3.3 Screening Process

A PRISMA flow diagram (Figure 5) was completed to illustrate the review process, including the number of records identified, included and excluded (Moher et al., 2009).

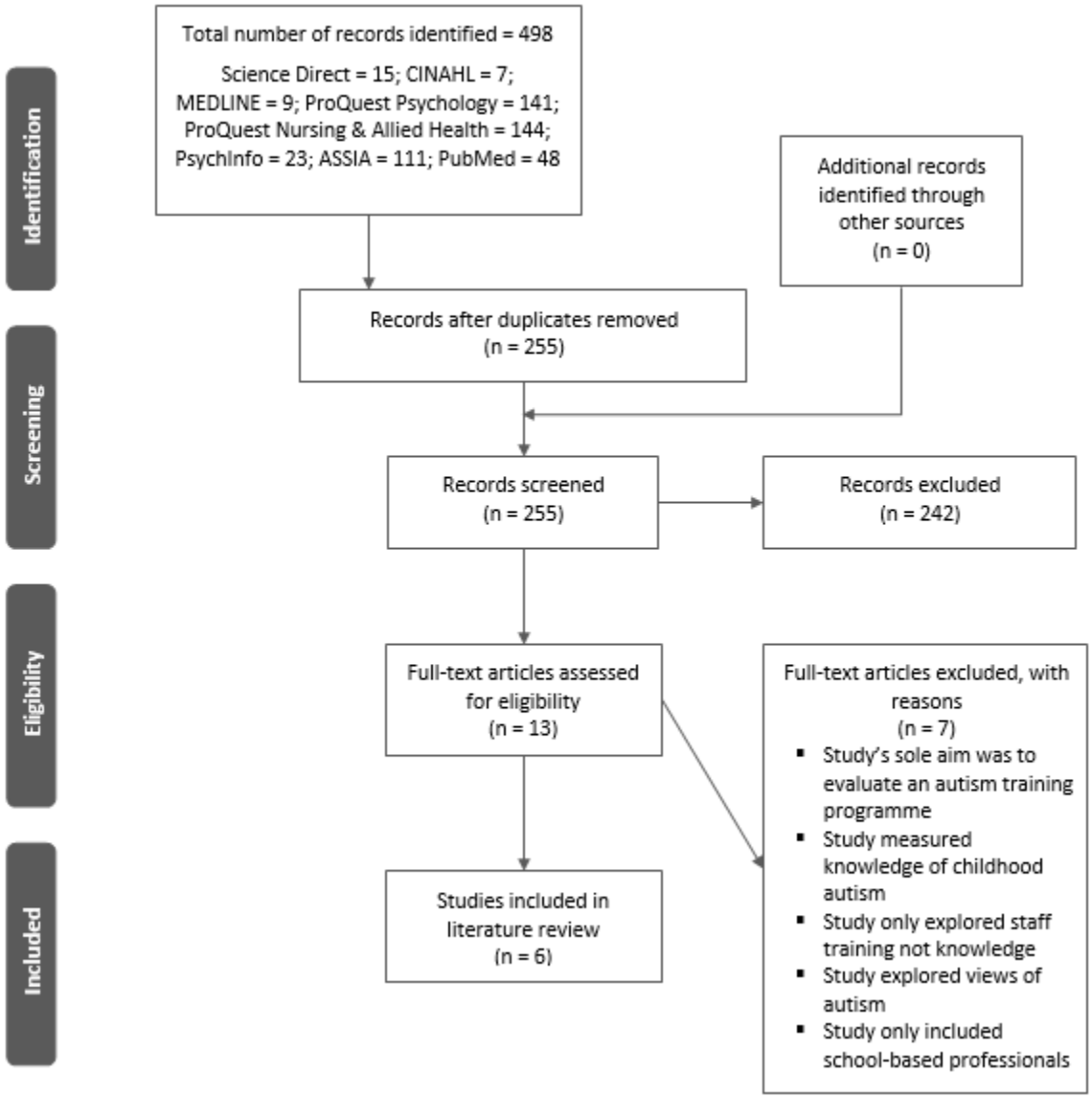

Figure 5: PRISMA flow diagram (Literature Review 2)

Of the 255 articles to be screened; 242 records were excluded after being screened at title/abstract level. Reasons for exclusion at the title/abstract level included, but were not limited to, articles not being relevant to healthcare professionals, articles not being specific to ASD, articles not being about knowledge of ASD, articles being about the experience of individuals with ASD rather than professionals' knowledge, articles

evaluating an intervention/programme, articles measuring knowledge of childhood autism, or articles exploring biological processes in ASD.

As shown in the PRISMA diagram above, a total of 13 articles were then screened at full-text level, six articles met the inclusion criteria for the current literature review. The six articles consisted of two mixed-methods studies, two quantitative studies and two predominantly quantitative studies (where qualitative analysis was also undertaken on the open-ended responses obtained from questionnaires). The below table provides the article citation, study population included, and the country in which the research was undertaken for the six included articles (Table 7).

Table 7: Article citations with corresponding study population and country of origin

Article	Study Population	Country
Clark et al. (2014)	Clinical and administrative staff working in Community Learning Disability Teams	UK
Zerbo et al. (2015)	Adult health care providers	USA
Unigwe et al. (2017)	General Practitioners (GPs)	UK
Crane et al. (2019)	Psychiatrists	UK
Knights et al. (2019)	Community Pharmacists	Australia
van't Hof et al. (2020)	Youth and Family Centre Physicians	The Netherlands

Criticial appraisal was undertaken on the six included articles using a Critical Appraisal Skills Programme (CASP) Checklist (CASP, 2018a). The modified version of the CASP Qualitative Studies Checklist (discussed earlier in the Phase 1 Literature Review, p.67) was utilised (CASP, 2018a). All six articles contained a clear statement of aims for their research and utilised appropriate methodologies (screening statements 1 and 2 on the CASP Checklist). Due to this, the remaining eight questions

on the CASP Checklist were completed for the six articles. To view the completed CASP Checklists, please see Appendix 5.

After critical appraisal had been undertaken, the six papers were synthesised and three key themes identified: (1) higher levels of ASD knowledge, (2) lower levels of ASD knowledge, and (3) the impact of autism training. The first theme, *higher levels of ASD knowledge*, included findings that related to healthcare professionals having adequate knowledge of ASD. On the other hand, *lower levels of ASD knowledge*, the second theme, discussed findings which indicated that healthcare professionals lack knowledge of ASD. *The impact of autism training*, the final theme, included articles that presented feedback that had been received following autism training from staff and evidences the impact that autism training can have on service delivery. Within the above mentioned themes, findings relating to healthcare professionals such as GPs will be discussed before healthcare professionals more specialist to mental health; therefore discussion within themes will gradually become more relevant to the focus of this thesis (mental health services). For example, within *higher levels of ASD knowledge*, GPs' and physicians' ASD knowledge will be discussed before the ASD knowledge of a Community Learning Disabilities Team and psychiatrists. This chapter will now move onto discuss the above mentioned themes that arose from the literature in relation to the Phase 2 Literature Review.

4.4 Phase 2 Literature Review Findings

4.4.1 Theme 1: Higher levels of ASD knowledge

Unigwe et al. (2017) aimed to explore UK based GPs' ASD knowledge, as well as their perceived self-efficacy, in identifying and supporting their patients on the spectrum. A knowledge of ASD scale as well a self-efficacy scale was completed by 304 GPs; the scales were based on existing scales but adapted specifically for this study. On the knowledge of ASD scale, respondents generally achieved high scores. After adjusting for chance responding, a mean score of 89.4% was calculated for the ASD scale. Statistical analysis found higher knowledge of ASD to be significantly correlated with a greater personal connection to autism ($r[303] = 0.19$, $p = 0.001$). Despite the GPs in this study generally having high levels of ASD knowledge, participants were found to be only somewhat confident in their ability to identify and support patients with autism.

The statement on the self-efficacy scale for which GPs self-reported most confident was 'Identifying stress in the parents and carers of my patients with autism' (Unigwe et al., 2017, p.5); this may indicate that GPs may not possess the knowledge/skills to identify autism in a patient but rather suspect autism as a result of a parent or carer's struggle. Unigwe et al. (2017) found higher self-efficacy to be significantly correlated to more training on autism (r[297] = 0.18, p = 0.002) as well as greater personal experience of autism (r[303] = 0.31, p<0.001). In relation to predicting GPs' self-efficacy, personal connections to autism (F[1,296] = 31.76, p<0.001) and autism training (F[1,295] = 11.46, p<0.001) were found to make a significant contribution to predicting GPs' self-efficacy. These findings suggest that autism training can improve professionals' confidence in working with people with autism. Although GPs do not play a role in diagnosing individuals with autism, they need to have enough knowledge to be able to recognise the key characteristics in order to know when to refer an individual on for ASD assessment.

Unigwe et al (2017) was the first study to use a reasonably large sample of UK GPs to explore GPs' perspectives on working with patients with autism. A point discussed by Unigwe et al. (2017) is that almost half of responders reported having some personal connection with autism. This may reflect a self-selection bias (Lavrakas, 2008) whereby individuals with an interest in autism might be more likely to participate. This highlighted limitation is likely true of all the studies in this literature review. The possible impact of this is that the GPs who took part may have higher knowledge than those who did not take part. This could mean that non-responding GPs may have a lesser knowledge of ASD, meaning that the findings of this study (and others) may be skewed. Additionally, two authors were involved in the undertaking of thematic analysis in this study, which increases the credibility of the themes identified (Nowell et al., 2017).

The knowledge of ASD in 93 physicians working at Dutch Youth and Family Centres (YFC) was evaluated by van't Hof et al. (2020). They explored both general and specific ASD knowledge in their sample; the specific ASD knowledge findings will be discussed later in this chapter. van't Hof et al. (2020) found physicians' mean general ASD knowledge score to be 7.1 (weighted mean). This score was on a 1 to 10 scale with 1 being least knowledgeable and 10 being most knowledgeable. For general ASD knowledge, only 9.7% of the physicians scored poorly on the scale (with 'poorly' being

considered answering less than 50% of the questions correctly). The lowest scoring statement for general ASD knowledge (68% of participants answered incorrectly) was about ASD in different ethnic and income groups; this indicates there may be a lack of knowledge surrounding the impact of ethnicity and socioeconomic status on ASD. This study found Dutch YFC physicians to have sufficient general knowledge of ASD, but a considerable number of physicians scored poorly on specific ASD knowledge. The findings of van't Hof et al. (2020) could suggest that physicians have an adequate understanding of ASD in general, but lack any depth of understanding.

van't Hof et al. (2020) utilised an ASD knowledge questionnaire to Youth and Family Centre (YFC) physicians to ascertain the ASD knowledge of this population. The utilised questionnaire, consisting of two parts, was self-developed for the study as a suitable questionnaire was not available to them. The ASD knowledge questionnaire was found to have low internal consistency (Part 1 Cronbach's alpha = 0.24, Part 2 Cronbach's alpha = 0.30) which indicates that it is weak as a construct for ASD knowledge (van't Hof et al., 2020). Even so, the high percentage of incorrect answers obtained on the questionnaire is suggestive of a gap in ASD knowledge. An additional limitation cited is that 95% of the sample was female; however, this may reflect the high proportion of female YFC physicians in the Netherlands (93%) (van't Hof et al., 2020). Selection bias was not a concern for this study as the course, and therefore the questionnaire, was compulsory for all YFC physicians in the Rotterdam municipality.

The ASD knowledge of staff working within Community Learning Disabilities Teams was investigated by Clark et al. (2014) using an electronic questionnaire. Both clinical staff (n = 43) and administrative staff (n = 13) completed the questionnaire and the results found that the majority of staff working within the adult Community Learning Disabilities service had a good basic understanding of ASD. It was found that staff generally had good knowledge of the difficulties individuals with autism experience, such as: sensory issues, understanding emotions, repetitive speech, seeing the bigger picture, and language processing, as well as a need for routine/structure. Weaker areas of knowledge included: how individuals with autism may interpret language literally, the fact that some people with autism can make eye contact, and the prevalence of people with both autism and LD. Clark et al. (2014) found administrative staff to have a more limited understanding of ASD compared to clinical staff. On average, clinical staff had the following percentages on the questionnaire: 90%

‘correct’ responses, 2% ‘incorrect’ responses and 8% ‘don’t know’ responses. Administrative staff had fewer correct (76%) responses and more ‘incorrect’ (4%) and ‘don’t know’ (19%) responses. This could be due to a lack of autism training for administrative staff; only 1 in 13 administrative staff had received autism training compared to 40 of the 43 clinical staff. Clark et al. (2014) contended that this indicates a need for administrative staff to be trained in autism (as well as clinical staff) as they are the frontline of the organisation. Although administrative staff do not clinically support individuals with autism, they may have a role in orchestrating their care (for example, dealing with service user queries and/or arranging appointments). Therefore, training to understand the difficulties faced by individuals with autism and ways in which administrative staff can help to alleviate those difficulties could improve the service experience of individuals with autism.

Clark et al. (2014) utilised both a questionnaire and focus group in their research. The utilisation of questionnaires in research can be advantageous, as questionnaires: can obtain data quickly from a large number of people, are low cost, and have a lack of interviewer bias; however, questionnaires also have their limitations (Gray, 2018). These include: generally low response rates, there being no opportunity for participants to ask questions to clarify meanings of statements (which could result in inaccurate/misleading responses), and there being no opportunity for researchers to ask participants why they have answered in a certain way (Gray, 2018). Contrastingly, focus groups provide the opportunity to identify collective perspectives, with group discussions allowing for ideas to be validated (Gray, 2018). Issues to be aware of when conducting focus groups include: the potential for confidentiality to be breached and the potential for focus groups being difficult to manage when conflicts arise during discussion (Gray, 2018). In the research of Clark et al. (2014), 56 participants completed the questionnaire, with 13 of these participants being administrative staff. Of these 13 administrative members of staff who attended autism training after completing the questionnaire, a subgroup of 8 took part in a focus group. The reason for why only 8 of these 13 were included in the focus group is not stated, and how these 8 were sampled from the 13 is additionally not clear. Clark et al. (2014) contributed to the literature by exploring the ASD knowledge of staff in community learning disability teams, comparing knowledge between clinical and administrative

staff, and by assessing the impact of autism training delivered to a cohort of administrative staff.

In relation to mental health professionals' ASD knowledge, Crane et al. (2019) utilised an online questionnaire to understand psychiatrists' experience in, and confidence of, working with individuals with autism. The online questionnaire included a Knowledge of Autism Scale on which the psychiatrists achieved high scores. A mean score of 90.6% was obtained (after adjusting for chance responding) by the 162 respondents that complete the scale. Crane et al. (2019) found the adjusted scores were significantly higher for psychiatrists with personal experience of autism (median 20.95) than those without (median 19.90), $U = 2570$, $p = 0.02$. The questionnaire also included a self-efficacy scale to measure participants' confidence in their ability to screen, diagnose and manage individuals with autism. This self-efficacy scale found respondents' confidence to range widely. The scales used by Crane et al. (2019) to measure ASD knowledge and self-efficacy were sourced from Unigwe et al. (2017) (discussed previously), although the self-efficacy scale was adapted to make it more specific to psychiatrists rather than GPs. Correlational analyses found higher self-efficacy to be significantly related to higher adjusted knowledge of ASD scores ($r[158] = 0.26$, $p = 0.001$) indicating a relationship between ASD knowledge and confidence in working with patients with autism.

Additional analyses revealed that self-efficacy scores were significantly higher for participants who had received training (median 7.05) compared to those who had not received autism training (median 4.68), $U = 523$, $p < 0.001$ (Crane et al., 2019). This finding suggests that autism training can give psychiatrists more confidence in supporting people on the spectrum. Over two-thirds of participants (n = 119, 69.2%) reported having received autism training during either their primary medical degree, foundation degree or specialist psychiatric training, with 69.8% (n = 120) receiving autism training since qualifying as a psychiatrist. In addition to the quantitative analysis, Crane et al. (2019) also undertook qualitative analysis on the open-ended responses obtained from their questionnaire which explored barriers to healthcare for individuals with autism. Seven themes were identified, but only one was relevant to the current literature review; the theme highlighted a need for better understanding of ASD, including for professionals beyond psychiatry. The respondents in this study suggested that a lack of ASD understanding could lead to misdiagnosis or failure to

recognise co-existing difficulties. Crane et al. (2019) called for more training for all multidisciplinary team staff, in order to improve patient care.

Crane et al. (2019) contributed to the literature by specifically exploring psychiatrists' knowledge, experience and confidence in working with patients with autism. A limitation of this study is its response rate; when considering approximately 7000 psychiatrists practise in the UK, the number of participants in this study equates to approximately 2.5% of psychiatrists in the UK (Crane et al., 2019). This impacts on the generalisability of the findings. Alike Unigwe et al. (2017), Crane et al. (2019) reported that due to just under half of respondents having a personal connection with autism, the sample may be biased. This means that the findings must be interpreted critically and that some of the issues raised may be an underestimation of the true picture. An additional limitation is the fact that more participants had adults with autism as patients (69.8%) compared to participants having children with autism as patients (28.5) which could have impacted on responses given.

4.4.2 Theme 2: Lower levels of ASD knowledge

In addition to exploring general ASD knowledge (discussed in previous section), van't Hof et al. (2020) explored the specific ASD knowledge of Dutch Youth and Family Centre (YFC) physicians. They found physicians' specific ASD knowledge score to be 5.7 (weighted mean, on a scale of 1-10 with 1 being least knowledgeable and 10 being most knowledgeable). In relation to specific ASD knowledge, 41.9% of participants scored poorly (answering less than 50% of questions correctly), therefore possessing a lack of ASD knowledge. When looking specifically at the five lowest scoring statements on the specific ASD knowledge section of the questionnaire, statements related to the following topics were answering incorrectly most frequently: (1) the specification of ASD in the DSM-5, (2) syndromes in ASD, (3) language, speech and communication problems in people with ASD, (4) possible early signs of ASD, and (5) comorbidity of ASD. By identifying the lowest scoring statements on the questionnaire, gaps in knowledge can be detected and training tailored. van't Hof et al. (2020) argued that there is a need for YFC educational programs to specifically address physicians' specific ASD knowledge.

Lower levels of ASD knowledge were also found by Knights et al. (2020) when they assessed the knowledge and understanding of ASD in community pharmacists using

a postal questionnaire. On their questionnaire a score of ≥10/13 (≥76.9%) was considered an indication of 'good' knowledge. Knights et al. (2020) found that 34/96 (35.4%) of respondents were classified as having 'good' knowledge. Of the 96 participants, 44/96 (45.8%) answered seven to nine statements correct, with 18/96 (18.8%) answering less than seven answers correct; these findings indicate that the majority of participants did not have 'good' ASD knowledge. The greatest uncertainty amongst the pharmacists was in relation to pathophysiology and causative factors of ASD. Statistical analyses demonstrated two significant associations; pharmacists recognising that (1) stigma exists in the community regarding autism and that (2) stigma increases disadvantage, were two variables that independently associated with 'good knowledge' (p <0.0001; and p = 0.0012 respectively). This study found pharmacists to lack the confidence in offering advice to patients with autism and their family members; the authors argue that additional skills appropriate to advising this population requires attention. Knights et al. (2019) concluded that respondents overall had a sound basic knowledge of ASD but lacked any depth of understanding, similar to the conclusion made by van't Hof et al. (2020). The work of Knights et al. (2020) suggests that community pharmacists have insufficient levels of ASD knowledge and also lack confidence in advising patients with autism and their family members.

Knights et al. (2019), utilised a postal questionnaire to specifically assess the ASD knowledge of community pharmacists. Stratified random sampling was employed for this study to achieve a greater degree of representativeness. An advantage of this type of sampling is that it increases the likelihood of key groups being in the sample, whilst still including an element of random selection (Gray, 2018). However, Knights et al. (2019) proposed that the sample obtained may still not be representative of all pharmacists in Western Australia (response rate = 38.8%) and it may be the case that only the most involved, enthusiastic pharmacists responded to the questionnaire. The questionnaire used in this study to measure ASD knowledge was informed by a number of existing questionnaires assessing community pharmacists' and other professionals' knowledge of ASD. This study contributed to existing literature by being the first in Australia to assess community pharmacists' knowledge of ASD and the appropriateness of pharmacies for people with autism.

A different approach to exploring ASD knowledge was utilised by Zerbo et al. (2015); they asked adult healthcare providers to self-rate their knowledge of ASD, with the

researchers also assessing the providers' ability to recognise ASD characteristics. Data was obtained through an online questionnaire that was completed by adult healthcare providers (n = 852). The sample comprised of physicians (n = 593), psychologists (n = 102), social workers (n = 68), marriage and family therapists (n = 31) and nurses (n = 58). Respondents were recruited from family and internal medicine (n = 429), adult mental health (n = 291), and obstetrics and gynaecology (OBGYN; n = 132). Respondents were asked to rate their knowledge/skills in providing care to ASD patients, and the majority of participants (77%) rated their ASD knowledge/skills as 'poor' or 'fair'. There were variations seen between the different services; for example, 88% of OBGYN providers rated their knowledge skills as poor or fair, followed by 79% of respondents in adult medicine, then followed by mental health providers at 70%. This indicates that healthcare providers across a variety of departments believe they lack ASD knowledge, which could impact upon their ability to support patients with autism. Respondents were also asked to identify patient characteristics that would lead the provider to exploring the possibility of ASD. The majority of adult healthcare providers correctly recognised the core characteristics of ASD. It was found that compared to medicine and OBGYN, mental health providers were found to be most knowledgeable about ASD characteristics. This finding together with self-reported ASD knowledge could indicate that mental health providers are more informed about ASD and/or have more contact with individuals with autism compared to professionals working in adult medicine and OBGYN. However, 70% of mental health providers still self-reported poor or fair knowledge of ASD. It could be contended that improving the ASD knowledge of professionals within the services included in this study would benefit service users with autism who access these services.

Zerbo et al. (2015) utilised an online questionnaire as well semi-structured interviews. The less constrained nature of semi-structured, open questions allows for richer and more genuine responses to be obtained, and provides the opportunity for interview questions to be adapted to the responses of the interviewee (Coolican, 2019). However, disadvantages of semi-structured interviews include problems with reliability and generalisability, the amount of time required for interviews (for both interviewer and interviewee) and that the time-consuming nature of interviews may limit the number of participants it is possible to interview (Coolican, 2019). In relation to questionnaire completion, Zerbo et al. (2015) highlighted the response rate was low

(25%) which could mean that those who completed the questionnaire might not be representative of the target population. Additionally, demographic and professional characteristics of the participants were not collected meaning that questionnaire responses could not be explored for variations by sex, age, race, or years of experience, with could result in meaningful associations being missed. Different to the other studies in this literature review, Zerbo et al. (2015) asked professionals to self-rate their knowledge of ASD. This needs to be taken into consideration when comparing findings across the papers, as measuring ASD knowledge through individuals' perceptions of their ASD knowledge is very subjective. It could be the case that a professional's perception of their ASD knowledge varies greatly from their actual level of ASD knowledge. In relation to data analysis, Zerbo et al. (2015) reported that only one researcher had analysed all the interviews and this may have affected the reliability of the interview findings; the credibility of qualitative analysis can be enhanced by having two researchers analysing the data set (Nowell et al., 2017). However, despite the study limitations, the work of Zerbo et al. (2015) contributed to the literature by measuring the self-reported ASD knowledge of a range of professionals across different disciplines, and by exploring physicians' comfort-level and experience of supporting patients with autism.

In addition to asking professionals to self-rate their ASD knowledge, Zerbo et al. (2015) also undertook follow-up qualitative interviews with a subset of physicians (n = 9) who had completed the online questionnaire. Qualitative analysis identified three themes, two of which are relevant to the current literature reviews: (1) a lack of ASD knowledge and (2) need for training and resources. Theme one, a *lack of ASD knowledge*, portrayed physicians' lack of familiarity with ASD, with all of the physicians reporting that they had received no formal training in the screening and/or diagnosis of ASD. Physicians who reported having knowledge of ASD had learnt about ASD through self-learning, presentations they attended or through having a personal connection to autism. A *need for training and resources* was the second identified theme which found that 8 of the 9 physicians stated that they had received little or no ASD training during medical school or residency. The one interviewee who had received training shared that whilst he knew about the diagnosis of ASD, he never learnt about how to support a patient with autism. Interviewees reported experiencing many frustrations in treating patients with autism such as having difficulty communicating with the patient (a barrier

to establishing rapport), which was frequently attributed to a lack of autism training. An additional topic that emerged from the interviews included provider bias; when physicians were asked if they would ask patients with autism the same questions as patients without autism, some physicians stated they did not talk about topics such as sex, drugs and alcohol with their patients with autism. In relation to whether a physician would ask the same questions, one doctor stated: "I would say no, and that probably is a bias. I think we assume, oh this person, they probably don't smoke, they probably don't drink alcohol, they're probably not having sex. I mean, that's just wrong, but … that's the reality" (Zerbo et al., 2015, p. 4009). This finding further highlights the need for autism training, as provider bias could have an effect on the standard of care that patients receive with this population potentially not being asked questions vital to their health and wellbeing.

4.4.3 Theme 3: The impact of autism training

In addition to the questionnaire distributed by Clark et al. (2014) (discussed previously), focus groups were undertaken with 8 administrative staff members after they had received autism training. This focus group was undertaken to allow administrative staff to reflect on their experience of the autism training and to discuss improvements that could be made to administrative practices for people with autism. Five themes arose from the focus groups: (1) feedback on autism training, (2) communication between administrative staff and clinicians, (3) making waiting environments more 'autism friendly', (4) communication with people with autism, and (5) future training. In relation to *feedback on autism training*, staff found the case studies relatable to their jobs and stated that the training had been delivered by staff who were able to provide informed and practical advice on real-life situations. Staff stated that using more simplistic language could improve the training. The second theme, *communication between administrative staff and clinicians*, identified a lack of consistent information from clinicians as a barrier to changing administrative practices. Administrative staff highlighted that they would like to know the following: which people using the service have autism (and their particular sensory needs and environmental preferences), how to communicate with people with autism (on the phone and in-person) and how best to inform people about appointment times. *Making waiting environments more 'autism friendly'* related to administrative staff wanting to provide the best sensory environment they can. Staff highlighted ways they had changed their

practice to do this, such as keeping on top of clutter in the clinic rooms and reception areas, and by offering alternative spaces for people with autism. The fourth theme, *communication with people with autism*, shared changes to staff practice that had happened after attending autism training including communicating in a clear and consistent way, ensuring patients know how things are done in a step by step way, giving the person time to respond, and being flexible with appointment times. The final theme, *future training*, highlighted the importance of including administrative staff in future training and to ensure newly recruited staff are provided with ongoing autism training. Overall the feedback from the autism training was very positive and demonstrated that immediate changes were made following the training that made services more autism friendly such as changing waiting room environments and communication practices. However, it must be acknowledged that every person with autism is different, so there is a need to obtain feedback from individuals with autism to establish whether the changes made improved their experience of the service. Clark et al. (2014) stressed the need for all frontline health staff, including administrative staff, to be given the opportunity to undertake autism training.

4.5 Literature Review Summary – Phase 2

In summary, this literature review found differing levels of ASD knowledge across the six papers. Clark et al. (2014) found staff (clinical and administrative) generally had good knowledge of the difficulties individuals with autism experience. In the research undertaken by Zerbo et al. (2015), which included varying professions from across family and internal medicine, adult mental health, and OBGYN, it was found that three-quarters of professionals rated their knowledge/skills as 'poor' or 'fair'. GPs were found to have high levels of ASD knowledge by Unigwe et al. (2017), but were found to be only somewhat confident in their ability to identify and support patients with autism. Crane et al. (2019) found high levels of ASD knowledge in psychiatrists, with psychiatrists obtaining a mean score of 90.6% on their Knowledge of Autism Scale. Contrastingly, Dutch YFC physicians were found to have sufficient general knowledge of ASD, but a considerable number (41.9%) scored poorly in relation to specific ASD knowledge (van't Hof et al., 2020). In relation to community pharmacists, only a minority (35.4%) were found to have good knowledge by Knights et al. (2020).

In relation to the research question being explored in this literature review, '*What knowledge of ASD exists amongst healthcare professionals?',* the answer is not clear. There appears to be differences between different professions (e.g. GPs, psychiatrists, pharmacists), and between different departments (family and internal medicine, adult mental health, OBGYN). No clear conclusions can be drawn due to the limited literature available (6 papers) in relation to this research question. Further research is required to help address this research question.

4.6 Gap in the Literature

The previous and current chapter has demonstrated that there is very limited evidence in relation to both of the following questions:

What are the needs and experiences of service users with ASD accessing healthcare? (Phase 1 Literature Review)

What knowledge of ASD exists amongst healthcare professionals? (Phase 2 Literature Review)

The literature reviews contained within this thesis were undertaken to explore the current literature available relevant to the current research project. The research questions relevant to the current PhD study that were explored through reviewing the literature were as follows:

What are the needs and experiences of service users with co-existing autism and mental health difficulties accessing adult mental health services? (Phase 1)

What knowledge of ASD exists amongst mental health professionals working within Adult Mental Health Services? (Phase 2)

In relation to the first research question, the first literature review contained within this chapter found only 3 papers which explored the mental health support experiences of adults with autism (Crane et al., 2018, Camm-Crosbie et al., 2018, and Maddox et al., 2019). Two of these studies were undertaken in the UK; one of the studies only included the experiences of young adults with autism in England (Crane et al., 2018) with the other being UK wide (Camm-Crosbie et al., 2018). Camm-Crosbie et al. (2018) do not provide a break-down of participants' nationalities within their study and therefore it cannot be confirmed that any participants were from Wales. The literature

review identified no studies which exclusively explored the experiences of adults with autism and co-existing mental health disorders of accessing mental health support within Wales. This could mean that the experiences of adults with autism in Wales of accessing mental health support have never been captured. Additionally, none of the studies identified specifically investigated the experiences of adults with autism in relation to a specific health board. Therefore, capturing the mental health support experiences of adults with autism from a specific health board within Wales would be a novel contribution.

In relation to the second research question, only 2 articles identified in the Phase 2 Literature Review included professionals working within mental health (Zerbo et al., 2015, and Crane et al., 2019). The first study by Zerbo et al. (2015), undertaken in the USA, asked mental health providers (34% of their sample) to self-rate their knowledge of ASD. On the other hand, Crane et al. (2019) objectively measured the ASD knowledge of psychiatrists in the UK using a Knowledge of Autism Scale which was an adapted version of the scale used by Unigwe et al. (2017). Therefore, according to the current literature review, no study has been undertaken which objectively measures the ASD knowledge of a variety of mental health professions. In conclusion, this study will address a gap in the literature by objectively measuring the ASD knowledge of a range of mental health professionals using an ASD knowledge scale, therefore making an additional original contribution to knowledge.

4.7 Chapter Summary

In summary, this chapter contains two literature reviews which explored: (1) the needs/experiences of service users with autism accessing healthcare, and (2) the knowledge/understanding of ASD that exists amongst healthcare professionals. The findings of the two literature reviews were discussed in relation to the research questions of this thesis. Gaps in the literature were identified and the original contributions of the current project were acknowledged. The following chapter provides details of the study's methodology, research design, method and analysis process.

Chapter Five: Methodology

5.1 Introduction

This chapter begins by stating the research questions before making a distinction between qualitative and quantitative methodologies; the need for a mixed-method approach in the current study will be conveyed. This is followed by a discussion of the sampling, recruitment, research materials, research procedure, and relevant analysis for both phases. Finally, the chapter will discuss ethical implications before quality in qualitative research is considered.

5.2 Research Questions

The current study aimed to address the following three research questions:

1. What are the needs and experiences of service users with co-existing autism and mental health disorder(s)?

2. Is the Health Board's adult mental health service meeting the needs of service users with co-existing autism and mental health disorder(s)?

3. What level of ASD knowledge do professionals working within adult mental health services in the Health Board possess?

5.3 Philosophical Worldview

Before discussing the methodology implemented in the current study, it is important to acknowledge the philosophical worldview that informed the study's methodology. A pragmatic worldview informed the undertaking of the current study, with pragmatism contending that the research question(s) should always be the most important focus of any research. Pragmatists advocate that researchers should utilise the best method(s) available to them, acknowledging that both quantitative and qualitative methods can be useful (Teddlie and Tashakkori, 2009). Due to this, pragmatism is commonly associated with mixed methods research (Creswell and Plano Clark, 2018) with pragmatists contending that mixing methods in a single study is not only legitimate, but in some cases necessary (Gray, 2018).

In relation to ontology and epistemology, pragmatism does not commit to any single system of philosophy and reality (Weaver, 2018). The pragmatist paradigm rejects a forced choice dichotomy between positivism/postpositivism and constructivism in relation to methods, ontology and epistemology; pragmatism instead embraces features associated with both points of view (Teddlie and Tashakkori, 2009). The ontological perspective of pragmatism is that both singular and multiple realities exist; pragmatists contend that researchers can both test hypotheses (in line with the positivist paradigm) as well as explore multiple perspectives (in line with the constructivist paradigm) (Creswell and Plano Clark, 2018).

Whilst ontology (discussed above) questions the nature of reality, epistemology explores the relationship between the knower and the known, in other words, the relationship between the researcher and the participant (Teddlie and Tashakkori, 2009). Positivists/postpositivists perceive research as objective, with separateness existing between the researcher and the participant, as where constructivists view research as subjective, with researchers and participants working in partnership to co-construct social realities (Teddlie and Tashakkori, 2009). Alternatively, pragmatists contend that objectivity and subjectivity should not be seen as two opposing poles, but rather on a continuum (Teddlie and Tashakkori, 2009). Pragmatism employs a principle of utilising "what works" in order to answer research questions, using varying methods and valuing both objective and subjective knowledge (Creswell and Plano Clark, 2018, p.39). In line with the pragmatist worldview, a mixed-method methodology was utilised for the current study, as using both a qualitative and quantitative method allowed for the research questions to be best addressed. The methodology will be discussed in further detail below.

5.4 Methodology

A methodology is the "framework of theories and principles on which methods and research strategies are based" (Holloway and Galvin, 2017, p.346), with both qualitative and quantitative methodologies available for use in research. Qualitative methodologies can be considered as iterative processes in which improved understanding is achieved by getting closer to the phenomenon being studied, with qualitative research attempting to make sense of phenomena through exploring the meaning that people attribute to them (Aspers and Corte, 2019). Alternatively, quantitative methodologies focus on objectivity, and rely on the "collection and

analysis of numerical data to describe, explain, predict, or control variables of interest" (SAGE, 2020, para.1). Please see below table for comparisons between qualitative and quantitative research methodologies.

Table 8: Comparisons between qualitative and quantitative research methodologies

	Qualitative	**Quantitative**
Epistemological positions	Constructivist	Objectivist
Relationship between researcher and participant	Close/insider	Distant/outsider
Research focus	Meanings	'Facts'
Relationship between theory/concepts and research	Induction/emergent	Deduction/confirmation
The nature of data	Data based upon text	Data based upon numbers

Source: Adapted from Gray, 2018

Qualitative or quantitative methodologies are often used in isolation, but can be used together. This approach is called a mixed-method methodology and this approach was appropriate for the current study. A mixed-method approach allowed for the needs and experiences of service users with co-existing autism and mental health disorder to be explored qualitatively, with mental health professionals' ASD knowledge being investigated quantitively. Gray (2018) highlighted that mixed method approaches are often utilised when a study has a variety of research questions which different methods are best suited to answer. This study adopted a mixed methods design. The main assumption of a mixed methods design is that the combination of both qualitative and quantitative can provide additional insight compared to what could be obtained by using either approach alone (Creswell and Creswell, 2018). Another benefit of mixed methods is that every research method has its own strengths and weaknesses and using mixed methods allows a method's weaknesses to be balanced out by alternative methods (Gray, 2018). Using both qualitative and quantitative methods in this study allowed for a more thorough exploration of the research topics.

Numerous typologies have been created to classify the varying types of mixed methods designs. The typologies have been made with differing foci; for example,

some typologies focus on the purpose for mixing methods and some focus on the sequencing of the varying methods (Creswell and Plano Clark, 2018). When utilising the typology created by Greene, Caracelli and Graham (1989), the mixed methods approach applied in the current study can be seen to serve two purposes: expansion and complementarity. Expansion seeks to extend the breadth of inquiry by employing methods most appropriate for exploring different inquiry components, whereas complementarity seeks to measure overlapping but also separate aspects of a phenomenon using mixed methods, which provides enhancement, elaboration and clarification of the results obtained from one method by using an additional method (Greene, Caracelli and Graham, 1989).

Alternatively, Johnson, Onwuegbuzie and Turner (2007) discussed a continuum of mixed methods research consisting of five different types of mixed methods research. When considering the current study, it would be considered a qualitative dominant mixed methods research project (QUAL + quan research). A definition of qualitative dominant mixed methods research is when a project mainly took a qualitative perspective, but recognised that adding a quantitative component is likely to benefit the research (Johnson, Onwuegbuzie and Turner, 2007). This project utilises this approach as the qualitative element was seeking to conduct an in-depth exploration of service user perspectives, whilst the quantitative element was seeking to measure staff knowledge of ASD and confidence in their knowledge. The data collection methods employed in both phases are illustrated below (Figure 6).

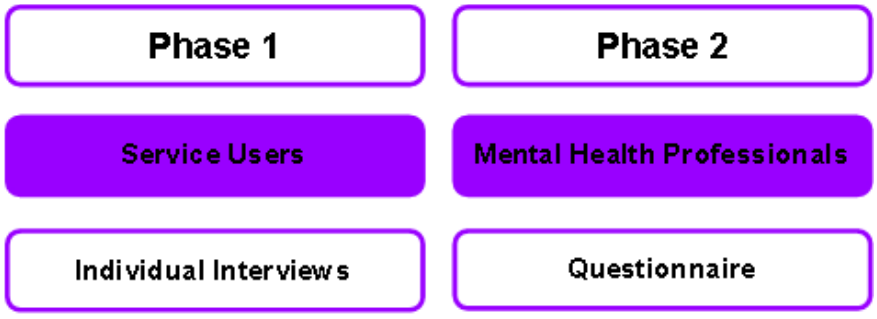

Figure 6: Visual depiction of Phase 1 and 2 data collection methods

In mixed methods research, the data collection methods can be conducted in a parallel manner or sequentially (Teddlie and Tashakkori, 2009). Parallel mixed designs involve the data collection methods in a study occurring at the same time, whilst sequential mixed designs mean that the methods are conducted in chronological order (Teddlie

and Tashakkori, 2009). In this study, the service user semi-structured individual interviews (Phase 1) were conducted at the same time as the ASD questionnaire was distributed (Phase 2). This means that the current study could be described as having a parallel mixed design.

For Phase 1, Interpretative Phenomenological Analysis (IPA) was employed as the methodology and for the analysis of the service user individual interviews. In Phase 2, the quantitative data generated by the questionnaire was scored and entered into SPSS (version 26) for analysis. The reasons for selecting IPA as a methodology will now be conveyed, before a description of IPA (including its development as a methodology from phenomenology) will be provided.

5.4.1 Selecting an appropriate qualitative methodology

When considering which methodology would be most appropriate for the current study, descriptive phenomenology, interpretative phenomenology and grounded theory were considered before deeming IPA to be the most appropriate. One key difference between descriptive and interpretative phenomenology is that descriptive phenomenology argues that the voice of the participant should be shared with nothing altered, whilst interpretative phenomenology contends that interpretation of a phenomena is inevitable, and that it is impossible for the researcher to be completely independent from the phenomena under investigation. Descriptive phenomenology (discussed above) was considered not to be the most appropriate methodology due the fact that the researcher of this study had spent time shadowing in mental health services to aid understanding of how the services worked, and therefore it would be difficult to for the researcher to set aside her knowledge of the service. Whilst the in-depth focus on the lived-experience of participants was shared with both descriptive and interpretative phenomenology, interpretative phenomenology allows participants experiences to be interpretated to allow service needs to be identified. Additionally, the knowledge that the researcher had gained during her shadowing could help to inform the analysis of the data.

An alternative methodology also considered was grounded theory. The approach of this methodology is different, with this methodology allowing theory to be developed that is grounded in the data (Braun and Clarke, 2013). Glaser and Strauss (1967) first developed grounded theory, with grounded theory proposing that qualitative data can

be used to develop theory (Gray, 2018). When using a grounded theory approach, theories are not applied to the participants being studied, instead theories emerge from the participant's data (Gray, 2018). When using grounded theory as a methodology, a researcher does not begin with predictive hypotheses or research questions (Gray, 2018), nor should they have preconceived theories or preconceptions (Holloway and Galvin, 2017). Grounded theory was deemed not to be an appropriate methodology for researching the current study as there were preconceptions involved and there were specific research questions to be answered; the overall aim of the study was not to generate new theory but to answer a particular research question from the experiences of service users. IPA was better suited as a methodology to the current study, as its focus is to provide in-depth exploration of participants' lived experience, and to interpret that experience, which was in line with the project research questions and aims.

The following section will discuss how phenomenology (both descriptive and hermeneutic) as well as idiography inform IPA as a methodology.

5.4.2 The Development of Phenomenology

Phenomenology dates back to the late 1800s/early 1900s when Edmund Husserl developed phenomenology as a philosophic method for investigating consciousness, based on the teachings of his professor Franz Brentano (Wertz et al., 2011). Over time phenomenology has also been applied to other disciplines such as the humanities, human sciences and fine arts (Wertz et al., 2011). In psychology, phenomenology is considered the qualitative study of human experience. In other words, phenomenology aims to see the world from the participant's point of view (Gray, 2018). The aim of phenomenology is to consider how situations are meaningfully lived as they are experienced (Wertz et al., 2011). When applying phenomenology to psychology, researchers focus on individuals' perceptions of their lives and what this means to them (Langdridge, 2007).

Phenomenology considers reality to be socially constructed rather than objectively determined (Armstrong, 2010) and therefore appreciates that it is impossible to achieve complete objectivity and neutrality in research as the values of participants are an essential part of the research (Holloway and Galvin, 2017). Phenomenologists argue that in order to understand social reality, you need to explore peoples'

experiences of that social reality (Gray, 2018). Phenomenological research requires the researcher to engage with the "participant's felt sense, their experience of 'how it is' for them to be in a particular situation, of 'what it is like' to have a particular experience" (Harper and Thompson, 2012, p.118). To do this, phenomenologists explore the meaning of individuals' lived experience through their own description (Holloway and Galvin, 2017).

Phenomenology does not aim to disregard natural science research or the existence of objectivity; phenomenology purely aims to extend science into the realm of subjectivity (Wertz et al., 2011). As a result, Phenomenology seeks subjective accounts and interpretations from participants using qualitative methods whilst emphasising inductive logic (Gray, 2018). The inductive approach first establishes facts and then builds theories/concepts based on these facts; in other words, moving from the specific to the general (Gray, 2018). Phenomenological data is predominantly collected through semi-structured interviews (Picton et al., 2017) using purposively selected participants who tend to share common experiences; this is so that detailed patterns of meaning and relationships can be identified (Gray, 2018).

Phenomenology has two main branches: descriptive and interpretative. In simple terms, descriptive phenomenology aims to reveal and describe the meanings of peoples' experiences, whilst interpretative phenomenology aims to interpret the meanings of people's experiences (Picton et al., 2017). Husserl's phenomenology was descriptive in nature, whereby everyday conscious experiences were described whilst preconceived opinions (of the researcher) were set aside or bracketed (Reiners, 2012). The descriptive approach requires the researcher to convey the participant's experience as uninfluenced by the researcher as much as possible (Langdridge, 2007). Descriptive phenomenology recognises that there is a need for something to be described exactly as it is, with nothing added and nothing taken away (Giorgi, 2012). Husserl (1973) proposed that phenomenology, or as otherwise termed descriptive psychology, is concerned with describing the essence of types of mental acts, such as seeing, imagining and believing, and unlike empirical psychology, is not concerned with causal explanations.

A student of Husserl's, Martin Heidegger, developed Husserl's phenomenology to create hermeneutic (interpretative) phenomenology. Hermeneutics moves beyond

describing an experience in order to seek the meanings that are within everyday happenings (Reiners, 2012). It was argued by Heidegger that our understanding of the world is the result of our interpretation of it (Reiners, 2012). Heidegger (1962) introduced the notion of "Dasein", which translates to "Being-there" (p.27). Dasein, in the context of phenomenology, can be understood as "the kind of being that belongs to persons" or "any person who has such being, and who is thus an 'entity' himself" (Heidegger, 1962, p.27). Heidegger believed existence was 'founded on an embodied being-in-the-world' whereby individual perception of the world is grounded in themselves in relation to the environment in which they live (Langridge, 2007). Heidegger's account of Dasein placed emphasis on both engagement with the world and lived time, but Heidegger claimed that accessing these elements would always involve interpretation (Smith, Flowers and Larkin, 2009). Heidegger argued that it is impossible for researchers to investigate phenomena in a neutral or detached way (Langdridge, 2007). He claimed that people (including researchers) cannot be separated from the world they live in, and therefore cannot bracket their ways of perceiving phenomena (Langdridge, 2007). In contrast to descriptive phenomenology, Heidegger argued that bracketing was not necessary because hermeneutics assumed prior knowledge (Reiners, 2012). Building on this, interpretative phenomenology suggests that the researcher actually becomes a part of the phenomenon as they are not able to remove themselves from the meanings identified from the data (Reiners, 2012). This idea can be corroborated by the following quotation: "Inquiry itself is the behaviour of a questioner, and therefore of an entity, and as such has its own character of Being" (Heidegger, 1962, p.24). Due to this, Heidegger argued that researchers become so immersed that this would confirm credibility of the findings (Reiners, 2012).

5.4.3 Interpretative Phenomenological Analysis (IPA)

IPA is a methodology that emerged from a combination of phenomenology (study of experience), hermeneutics (theory of interpretation) and idiography (examination of the particular) (Smith, Flowers and Larkin, 2009). IPA emerged in the mid-1990s, developed by Jonathan Smith, drawing on concepts and ideas that have a much longer history (Smith, Flowers and Larkin, 2009). IPA is considered phenomenological as it tries to get as close as possible to the participants' personal experience, but is also hermeneutic as it recognises the interpretative journey involved for both participant and researcher (Smith, Flowers and Larkin, 2009). The overall aim of IPA

is to obtain rich, in-depth descriptions of how participants have experienced the particular phenomenon that is being explored (Pietkiewicz and Smith, 2014). IPA is considered to involve a 'double hermeneutic', meaning that whilst the participant is making sense of their experience, the researcher is making sense of the participant (Smith, Flowers and Larkin, 2009). In other words, the end result of IPA will inevitably be an account formed by the researcher of how they think the participant is thinking (Smith, Flowers and Larkin, 2009). As such, IPA is a dynamic process whereby the researcher plays an active role in the analysis process (Sullivan and Forrester, 2019). The concept of the hermeneutic circle is also important to the IPA process. The hermeneutic circle is the idea that there is a dynamic relationship between the part and the whole (Smith, Flowers and Larkin, 2009), and between the whole and its context, which will enable greater meaning to be established (Wertz et al., 2011). In other words, "to understand any given part, you look to the whole; to understand the whole, you look to the parts" (Smith, Flowers and Larkin, 2009, p.28). This principle operates at a number of levels; for example, the relationship between the single word and the sentence, between an extract and the complete text, and between an interview and overall research project (Smith, Flowers and Larkin, 2009). In the hermeneutic circle, prior familiarity with the research topic feeds into a repetitive, logical discussion with each new encountering of data, which involves a toing and froing between the parts and wholes in the research (Wertz et al., 2011). Researchers inevitably have fore-understandings of their research topic, based on their topic knowledge and personal life experience; sometimes these understandings are reaffirmed and sometimes they are altered based on their encounters with the data (Wertz et al., 2011). When interpreting data, researchers must resist the temptation to fit data into pre-determined themes according to their existing experience and allow the themes to arise from the data itself (Wertz et al., 2011).

As well as being informed by phenomenology and hermeneutics, IPA is also influenced by idiography. Idiography is concerned with examining the particular. In relation to IPA, this focus on the particular arises in two ways: (1) in the sense of the detail/depth of analysis undertaken, and (2) the commitment to understanding how a particular experiential phenomena has been perceived, from the perspective of particular individuals, in a particular situation (Smith, Flowers and Larkin, 2009). In other words, implementing the idiographic approach in IPA involves undertaking in-

depth analyses on individual cases, examining the participants' perspectives in their unique contexts (Pietkiewicz and Smith, 2014). Pietkiewicz and Smith (2014) argue that this idiographic commitment is unusual, even among qualitative methodologies. When using IPA to study a particular group of people, the researcher should discuss the key themes generated, using quotes to support the themes identified, and use individual narratives to show similarities and differences between individuals (Pietkiewicz and Smith, 2014).

5.4.4 Evaluation of IPA in relation to the current study

Some proposed advantages of using a phenomenological approach include how it can aid the understanding of peoples' meanings, contribute to the development of new theories and how it has the ability to gather data which is natural rather than artificial (Armstrong, 2010). In addition, due to the phenomenological approach emphasising the inductive obtaining of large quantities of data, it is more probable that information will be discovered that was not the original research focus (Gray, 2018). Alternatively, disadvantages of phenomenological research include the time-consuming nature of data collection and the potentially difficult analysis and interpretation of data (Armstrong, 2010). Additionally, Holloway and Galvin (2017) discuss what could be considered a disadvantage of phenomenological research in that detailed replication of a phenomenological research project would be unattainable as the research is dependent on many factors including research relationship, history, and location of participants.

In relation to the current study, Picton et al. (2017) argued that phenomenological research is well suited to the study of people with mental illness and their experiences. They argue that phenomenological research conforms to contemporary healthcare (person-centred care) by including peoples' experiences and enabling silent voices to be heard (Picton et al., 2017). Similarly, Howard, Katsos and Gibson (2019) contended that certain features of IPA such as its commitment to an equality of voice and research reflexivity may help to shed light on the experiences of individuals with autism. Mental health research has developed over the last three decades and now acknowledges the value in seeing peoples' experiences of mental health as a body of knowledge and expertise (Picton et al., 2017). In fact, Picton et al. (2017) claimed that there is a

therapeutic benefit to be had by service users who take part in phenomenological research.

An advantage of IPA is that it can be considered a wholesale qualitative methodology as it is not simply an analytical method; IPA details the underpinning theoretical principles, gives examples of suitable research questions and designs, and also suggests appropriate data collection strategies and analytical procedures (Braun and Clarke, 2013). Wertz et al. (2011) discusses the value of IPA studies being able to offer intricate analyses of particular aspects of lived experience, and argue that analysing data on a specific topic of importance to the participant can be seen as making a significant contribution to psychology. The above description of IPA is relevant to Phase 1 of the current study, where service users' experiences of adult mental health services were explored using this methodology.

5.4.5 Quantitative Methodology

In contrast to Phase 1, Phase 2 utilised a quantitative methodology whereby an online questionnaire was distributed to mental health professionals to measure professionals' ASD knowledge. The quantitative approach undertaken was non-experimental as there was no manipulation of any variable in the study (SAGE, 2020). The quantitative analysis undertaken explored relationships between variables, but it's important to remember that a correlation or any other relationship does not mean causation. Quantitative approaches focus on objectivity, and aim to generalise their findings to wide audiences (SAGE, 2020). Therefore, the findings from the statistical analyses undertaken on the Phase 2 data will generate results that could be generalised across adult mental health services in the Health Board. This chapter goes on to discuss the sampling, recruitment, research materials required, research procedure, and relevant analysis for both phases. The following content will be divided with Phase 1 being discussed before Phase 2 to help with clarity and understanding.

5.5 Phase 1

5.5.1 Sampling and recruitment

Non-probability sampling (also known as non-random sampling) was employed in this phase, specifically purposive, homogeneous sampling. Non-probability sampling can be described as a range of techniques that obtain samples whose findings will

necessitate interpretation before they can be extrapolated to the wider population (Gray, 2018). Purposive sampling is a type of non-probability sampling whereby particular individuals are purposefully selected as they can provide the best perspectives on the phenomenon being explored (Gray, 2018). In other words, particular individuals are selected because of their specific experiences or because of their expertise on a topic (Coolican, 2014). The sampling employed was also homogeneous because it involved the selection of a "small, homogenous group" who share common experiences; this allows understanding and patterns to be established (Gray, 2018, p.216). The homogenous sample in the context of the current study were individuals with co-existing autism and mental health disorder(s), who had accessed Adult Mental Health Services. The detailed inclusion criteria are detailed in the table below.

Table 9: Inclusion Criteria for Phase 1

Phase 1
▪ Must be aged between 18 and 65 years ▪ Must be from within the West Wales and Valleys region • Must have (diagnosed) co-existing ASD and mental health disorder • Must have the capacity to consent ▪ Must be currently accessing Mental Health Services within the Health Board, or have accessed the service within the last 12 months

Access to participants was facilitated by the health board, whereby approved recruiters approached/contacted service users who were deemed eligible to take part in the study. The recruiters consisted of three Occupational Therapists, one Clinical Research Officer and two General Practice Managers. The recruiters either discussed the study face-to-face with service users who met the inclusion criteria, or contacted them through the post. Participants were issued with a Participant Pack which consisted of a Participant Information Sheet (see Appendix 6), a Permission to Contact Form (see Appendix 7), and a prepaid envelope addressed to the researcher. For service users contacted through the post, an invitation letter from the recruiter was included (for the template invitation letter, see Appendix 8). If the service user wanted

more information about the study, or were keen to take part, they were advised to complete the Permission to Contact Form and return it to the researcher, or they could return it to the recruiter if the service user was approached face-to-face.

A total of 90 service users were contacted regarding the study, and 23 Permission to Contact Forms were returned to the researcher. Twenty participants took part in Phase 1 of the study, two service users did not meet the inclusion criteria for the study, and one service user decided they were no longer interested in taking part. All 20 participants participated in the study by undertaking a semi-structured individual interview, face-to-face. Eleven participants identified as female, eight participants identified as male, and one participant preferred not to say. The mean age of the participants from Phase 1 was 34.5 years; the youngest participant was 19 years old and the oldest was 55 years old. The mean age of ASD diagnosis was 27.75 years for the total sample. However, when mean age of ASD diagnosis was explored by sex, sex differences were revealed, with the mean age of female ASD diagnosis being 36.64 years (to 2dp) compared to 17.25 years of age for males (see below table).

Table 10: Mean age of ASD diagnosis by sex

Sex (self-reported)	N	Mean age of ASD diagnosis (years)
Female	11	36.64 (to 2dp)
Male	8	17.25
Prefer not to say	1	14
Total	20	27.75

Of the 20 participants who took part, 8 reported that they had the diagnosis of ASD as well as at least one other developmental disorder. The co-existing developmental disorders present in the sample included: Dyslexia, ADHD, Dyspraxia and Dyscalculia. Additionally, 13 participants reported that they had at least one mental health diagnosis prior to receiving their ASD diagnosis. As well as having an ASD diagnosis, all participants had to have autism and a co-existing mental health diagnosis to be eligible to take part. The participants had varying mental health diagnoses; mental health diagnoses that were reported included: Depression, Recurrent Depressive Disorder, Anxiety, Generalised Anxiety Disorder, Obsessive Compulsive Disorder, Bipolar Disorder, Post-Traumatic Stress Disorder, Borderline Personality Disorder, Gender Dysphoria and Alcohol Dependency.

When asked who had referred them to their current mental health service, 13 stated it was their GP, 4 stated they had been referred by the Child and Adolescent Mental Health Service (CAMHS) and 3 had been referred by the Crisis Team. The above information demonstrates the range of experiences that have been captured in this research, even though the service users included in this research project could be considered a niche population. All the information reported above on sample demographics is based on self-reported data from the participants.

5.5.2 Research Materials

The table below summarises the documents that were required for the first phase of this research project, with corresponding Appendices.

Table 11: Table detailing Phase 1 materials and corresponding appendices

Document	**Appendix Number**
Participant Information Sheet (Service Users)	6
Permission to Contact Form	7
Template Invitation Letter	8
Recruitment Poster for GP Practices	9
Interview Questions	10
Consent Form	11
Demographic Form	12
Debrief Form	13
Confirmation of Capacity Form	14

The Participant Information Sheet provided the participants with detailed information such as the purpose of the study, what participation would involve, the disadvantages and benefits of taking part, study contacts, information about confidentiality, and links to relevant websites. The Permission to Contact Form contained a brief introduction to the study and then asked for the individual's preferred contact details. The Permission to Contact Form allowed the researcher to contact the service users about the study. If the service user was approached by post, an Invitation Letter was used. The Invitation Letter provided the project title, researcher contact details and was signed by the recruiter. The letter reinforced that there was no obligation to take part. In addition to professionals recruiting, a Recruitment Poster was also designed to be displayed in GP Practices (see Appendix 9). The poster succinctly detailed the

eligibility criteria and what participation would involve, and contained the researcher's contact details.

At the consent meeting, the researcher had to determine whether the participant had capacity in order to take part in; capacity was considered in the context of the *Mental Capacity Act 2005*. Capacity was confirmed and recorded by the researcher on the Confirmation of Capacity Form. If the participant was deemed to have capacity, informed consent would then be taken. The Consent Form contained 9 statements that the participant had to initial to confirm their consent. It was on the consent form that the participant decided whether they would like to participate in the research online or face-to-face, in either a focus group or individual interview setting. The participant then had to complete the form by printing their name, dating the form, and signing their signature. Once consent was obtained, the participant completed the Demographic Form asking questions such as age, sex, ethnicity, employment, etc. The Demographic Form also contained questions about the participant's mental health disorder diagnoses (previous and current), neurodevelopmental disorder diagnoses, and their referral into their current mental health service. The participant was provided with the interview questions prior to the interview.

The interview questions were specifically devised for this research project to answer Research Questions 1 and 2. There were 16 pre-determined interview questions in total (see Appendix 10). All 16 questions were open-ended, to allow service users to elaborate on their answers. These questions were given to participants before the individual interviews to allow the participants to consider their answers. Interviews are seen as an appropriate phenomenological research method due to their exploratory nature, whereby two individuals can work together in the pursuit of cooperative enquiry (Gray, 2018). A service user with co-existing autism and mental health condition read the questions prior to the questions being submitted to ethics to ensure the questions were comprehensible for the target population (see further information on Public and Patient Involvement below). A Debrief Form was provided to the participant following the interviews. The Debrief Form contained a brief study overview, the research team's contact details and links to relevant websites. The interviews were audio recorded for later transcription; two audio recorders were utilised to ensure that there was a back-up of the recording in case there was an issue with one the recorders.

5.5.3 Public and Patient Involvement

Public and Patient Involvement (PPI) is defined by the National Institute for Health Research (NIHR) as "research being carried out 'with' or 'by' members of the public rather than 'to', 'about' or 'for' them"; having patients contribute to how research is designed and conducted can help to improve the quality and relevance of research of the population being explored (NIHR, 2021, para.4). Health Research Authority / INVOLVE (2016) highlight that PPI can also make research ethical by: making research more relevant, by helping to establish what is acceptable to participants, by improving the consent process and by enhancing service users' experience of participating in research.

The current study had PPI with a service user with co-existing autism and mental health disorder being involved in the design of the study at an early stage; the service user was a member of the steering committee, attending meetings with the research student, the student's supervisory team, and the health board's Clinical Advisor. The service user representative in the current study was involved in discussions about how best to undertake Phase 1 of the current study, and also read all research documentation relevant to Phase 1 of the study to ensure that it was appropriate for the target population. The service user emphasised the importance of giving potential participants choice, specifically in the mode of research they partook in (individual interview or focus group, and face-to-face or online) as he stated that people often make assumptions without asking what individuals would prefer. Additionally, his contribution helped to ensure that the questions service users were being asked in their interviews were relevant to them and sensitive. In summary, the service user representative, an expert by lived experience, helped to ensure that the research being undertaken was relevant to adults with co-existing autism and mental health disorder accessing mental health services, and that the research was conducted in a way that provided choice and respected participants' preferences.

5.5.4 Research Procedure

Following receipt of a Permission to Contact Form (see Appendix 7) from a service user, the researcher contacted the service user to discuss the study. If following this discussion the service user wanted to take part, a time, date and location was arranged for the researcher and service user to meet. During this meeting, the Participant

Information Sheet was discussed and the service user was given the opportunity to ask any questions they had about the study. If the service user wanted to take part, they were asked to complete a consent form (see Appendix 11), and to indicate if they would prefer to participate in an individual interview or focus group, either face-to-face or online. In the current study, all service users participated in face-to-face individual interviews. Following consent, the service user was also asked to complete a Demographic Form (see Appendix 12). At this meeting, the service user was provided with the interview questions (see Appendix 10) to consider prior to their interview. Participants were informed that the interview was semi-structured and that the researcher may ask additional questions to those detailed on the interview schedule. A second meeting was then scheduled for the interview to take place.

At the beginning of the second meeting, participants were reminded that they could discuss all teams within the mental health service such as primary care, acute wards, community teams, crisis teams, etc. In addition, participants were asked which terminology they preferred: 'autistic person' or 'person with autism'; this question was asked so that the current thesis could adopt this terminology to respect the participants' preferences. The participants were then asked the questions that they had been provided with in advance; the mean duration of the individual interviews was 52 minutes (to the nearest whole minute). The shortest interview was 26 minutes and 5 seconds, and the longest interview was 97 minutes and 38 seconds. In total, 17 hours, 17 minutes, and 31 seconds of data was collected and analysed, equating to 197,257 words of transcription. The individual interviews took place at a health board premises (chosen by the participant) at a date and time to suit the participant. The individual interviews were audio recorded for later transcription. The individual interviews were brought to a close with a research debrief (see Appendix 13) and by the researcher thanking the service user for their participation.

5.5.5 Data Analysis

The researcher transcribed the interview recordings verbatim. The researcher undertaking the transcription aided the ability of the researcher to become immersed in the data in readiness for analysis. All names and any potentially identifiable information were removed from the transcripts to maintain the anonymity of participants.

Smith, Flowers and Larkin (2009) detailed a flexible framework for undertaking IPA for researchers unaccustomed to employing IPA. The authors state that there is no clear right or wrong way to undertake IPA, but they acknowledge that those newer to IPA will need a more structured approach to undertaking IPA than some general guiding principles (Smith, Flowers and Larkin, 2009). The below table briefly outlines the steps described by Smith, Flowers and Larkin (2009) to assist the undertaking of IPA project.

Table 12: Table describing the IPA analysis process (based on Smith, Flowers and Larkin, 2009)

Step 1: Reading and re-reading	This step involves the researcher becoming immersed in the participant's transcript. They do this through reading, and re-reading the data, and through listening to the recording of the interview. This results in the researcher becoming actively engaged with the data, which will allow the analyst to start entering the participant's world.
Step 2: Initial noting	In this step, the analyst keeps an open mind and makes note of anything of interest within the transcript. Doing this ensures that the analyst becomes familiarised with the transcript; this allows the analyst to recognise the ways in which the participant discusses, understands and considers the phenomenon in question. Three different types of comments should be made on the transcript: descriptive, linguistic and conceptual.
Step 3: Developing emergent themes	In this step, the data set will include both the participant's transcript and the exploratory comments made in Step 2. The aim in this step is to reduce the volume of detail whilst keeping the complexity of the data; this means the analyst will work primarily with the initial notes in this stage. The main task in this step is to turn the notes in themes. Themes are normally linked to the psychological nature of a transcript; themes should be both grounded (focus on the particular) and conceptual (bigger picture). The themes will reflect the participant's experience and the interpretation of the analyst.

<u>Step 4:</u> Searching for connections across emergent themes	This step requires the analyst to map how they think the themes fit together. Not all of the emergent themes have to be involved in this level of analysis; some themes may be shelved. The themes incorporated will be dependent on the research question of the project. This step of the analysis creates super-ordinate themes, which contain themes. Techniques such as abstraction and subsumption will assist this step.
<u>Step 5:</u> Moving to the next case	Step 5 involves the analyst moving onto the next participant's transcript, and repeating the process detailed above. It is important that the analyst considers each transcript as a new case, trying not to impose ideas from previous analyses onto other transcripts. The analyst needs to allow the new themes to emerge for every transcript. The above steps repeat until all transcripts have been analysed.
<u>Step 6:</u> Looking for patterns across cases	This final stage involves the analyst looking for patterns across the participants. Are there any connections? Which themes are the most prevalent? Analysts can create a table of themes, showing the themes contained within super-ordinate themes, and then demonstrate the theme for a variety of participants using quotes.

The procedure detailed above, based on the framework provided by Smith, Flowers and Larkin (2009), was followed in the current study. However, Smith, Flowers and Larkin (2009) state that analysis is open to change, and only becomes final when it is being written up. This means that the steps provided above are not a rigid set of instructions that must be followed, but rather a guide to support analysts in the undertaking of IPA. When working with larger samples, Smith, Flowers and Larkin (2009) state that inevitably the analysis of each individual transcript cannot be as detailed as it would be for smaller samples. They suggest that the analyst identifies the emergent themes in each transcript, and then searches for patterns/connections across all the transcripts together (Smith, Flowers and Larkin, 2009). However, it is important to ensure that the idiographic focus of IPA is not lost when analysing a large

number of transcripts. Due to the fact that the current study had 20 participants, a detailed examination of each case was undertaken before moving to the group level of analysis, which explored the similarities and differences across the accounts. This enabled shared themes to be generated that still allowed for distinct voices and experiences to be captured. It is argued that even when the analysis is being undertaken at a group level, the analysis can still be considered IPA as the group level themes identified are evidenced by quotations provided by the individual participants (Smith, Flowers and Larkin, 2009). As part of the analysis process, the researcher created tables for each participant that illustrated how a participant's quotations corresponded with a particular subordinate theme, and which superordinate theme this sat within. Please refer to Appendix 15 to see two case examples of this. These tables evidence how idiography was maintained even whilst operating at a group level of analysis.

5.6 Phase 2

5.6.1 Sampling and recruitment

Similar to Phase 1, purposive, non-probability sampling was employed. In this phase, a diverse purposive sample (or heterogeneous sample) was obtained; diverse sampling involves "maximising differences to gain multiple perspectives" (Sullivan and Forrester, 2019, p.323). This sampling technique allowed for a variety of mental health professionals (including students) working within Adult Mental Health Services to be recruited. The inclusion criteria for Phase 2 are described in the below table.

Table 13: Inclusion Criteria for Phase 2

Phase 2
▪ Must be working for the Health Board ▪ Must be a working within Adult Mental Health Services (staff or student) ▪ Mental Health Staff can include (but are not limited to): nurses, occupational therapists, psychologists, psychiatrists, social workers, and health care support workers.

The health board's Research and Development Team distributed the Participant Information Sheet (see Appendix 16) and online questionnaire (see Appendix 16) to relevant team leaders who were asked to distribute the questionnaire onto their team members. Due to the way the questionnaires were distributed (this method of distribution was ethically approved), no meaningful participation/response rate could be ascertained.

Fifty-eight mental health professionals completed the 'Knowledge and Understanding of Autism Spectrum Disorder' questionnaire. The 58 participants comprised of the following occupations: nurse, psychiatrist, psychologist, assistant psychologist, social worker, occupational therapist, support worker, mental health nursing student, CBT therapist, specialist psychotherapist, art psychotherapist and therapist. Please see below table for the number of participants by occupation.

Table 14: Table showing participant numbers by occupation

Occupation	Number of Participants
Nurse	24
Occupational Therapist	15
Support Worker	7
Social Worker	4
Psychiatrist	1
Psychologist	1
Assistant Psychologist	1
Mental Health Nursing Student	1
CBT Therapist	1
Specialist Psychotherapist	1
Art Psychotherapist	1
Therapist	1
Total	**58**

The above table demonstrates that a variety of participants took part in the online ASD questionnaire. These occupations were then grouped into 3 categories for analysis: Nursing, Therapies and Social Care. Please see below table showing occupation categorisation.

Table 15: Table showing categorisation of occupations, and number of participants by occupation category

Nursing	Therapies	Social Care
▪ Nurse ▪ Mental Health Nursing Student	▪ Occupational Therapist ▪ Psychiatrist ▪ Psychologist ▪ Assistant Psychologist ▪ CBT Therapist ▪ Specialist Psychotherapist ▪ Art Psychotherapist ▪ Therapist	▪ Support Worker ▪ Social Worker
N = 25	**N = 22**	**N = 11**

5.6.2 Research Materials

A Participant Information Sheet for mental health professionals was distributed along with a URL link to the ASD questionnaire. The Participant Information Sheet (see Appendix 16) for staff contained the same sort of information as the document for service users, but just relevant to Phase 2 of the project. The Participant Information Sheet and questionnaire was distributed by email to relevant mental health professionals/teams by the Health Board's Research and Development Team. The questionnaire was designed on Online Surveys; this programme is fully compliant with all UK data protection laws. The 'Knowledge and Understanding of Autism Spectrum Disorder (ASD)' questionnaire was created specifically for the purposes of this study (see Appendix 17). The ASD questionnaire itself was developed from three pre-existing questionnaires (Kuhn & Carter, 2006; Bauer et al., 2015; & Hansen, 2015). The questionnaire first asked participants to select their occupation, indicate their year of qualification and provide details of previous ASD training they may have been offered, or undertaken. The questionnaire developed for this study was designed for professionals who work with adults therefore questions about ASD in childhood were largely excluded, or the wording altered. For example, one statement from Kuhn & Carter (2006) was changed from "Children with autism cannot show affection" to 'Individuals with ASD cannot show affection' (p.575). Additionally, some questions from the original questionnaires had to be amended to make them relevant to the population of the study. For example, the term 'Intellectual Disability' was changed to

'Learning Disability' (as this term is more commonly used in the UK), and 'Applied Behaviour Analysis' (an approach more commonly used with children) was substituted with 'Dialectical Behaviour Therapy'. Statements involving specific statistics were also not included, such as "About 75% of individuals with ASD/autism also meet criteria for obsessive-compulsive disorder" (Hansen, 2015, p.56). These statements were not included as statistics are specific to certain areas/countries; excluding statistics means that in the future this questionnaire could be utilised in various settings.

The questionnaire consisted of 28 questions, (part a and part b). Part a questions were statements about ASD knowledge to which participants had three possible answers: TRUE, FALSE or REALLY DON'T KNOW. The option of REALLY DON'T KNOW meant that participants were not forced to guess an answer if they really did not know if a statement was TRUE or FALSE; guessing would have affected their true knowledge score. Part b questions required participants to rate their confidence in the answer they provided to part a; the available answers were: NOT AT ALL CONFIDENT, CONFIDENT or VERY CONFIDENT. Hansen (2015) utilised a confidence rating on her ASD questionnaire as a way of capturing "actual knowledge" and "perceived knowledge" (p.18). In the current project, the confidence rating allowed an ASD confidence score to be generated for each participant, and for patterns in confidence across individual statements to be examined for the entire sample. The questionnaire finished with a Study Debrief Form.

5.6.3 Research Procedure

Participants accessed the questionnaire online through Online Surveys, after being emailed the link. The first page of the survey restated that the results of the questionnaire were anonymous, and contained some questions such as participant occupation, asked the year of participant qualification, and questions about the participants' previous ASD training (see Appendix 17 for ASD questionnaire).

Then the participant proceeded on to the ASD questionnaire containing the 28 (part a and part b) questions. Prior to completing the questions, there was a paragraph asking the participant to only put an answer of REALLY DON'T KNOW (part a questions) if the participant had no idea of the correct answer. The participant then completed the 28 questions. There was then a final page that contained a short debrief containing information about the study, team contact details and relevant training links. The mean

time taken to complete the questionnaire was 12 minutes (to the nearest whole number).

Implied consent was obtained from participants in this phase of the study; the participant completing and submitting the questionnaire implied their consent to take part and for their data to be used in the study.

5.6.4 Data Analysis

Responses from the questionnaires were marked and scored manually by the researcher. The questionnaires (part a only) were first marked by the researcher using the answer sheet (see Appendix 18); then the researcher moved onto scoring. For part a statements, a correct answer was scored 3, an incorrect answer was scored 2 and a response of REALLY DON'T KNOW was scored 1. For part b statements, NOT AT ALL CONFIDENT was scored 1, CONFIDENT was scored 2, and VERY CONFIDENT was scored 3. Whenever a participant had given a response of REALLY DON'T KNOW to a part a statement, the part b score was always 1. Once scored, the questionnaire scores were manually inputted into SPSS (version 26). ASD knowledge scores and ASD confidence scores were dependent variables; additional information such as the participants' occupation, occupation category, years since qualification, and whether professionals had undertaken ASD training were also entered into SPSS for analysis as independent variables. A mix of both parametric and non-parametric tests were utilised for analysis due to the ASD knowledge scores having non-normal distribution. Six research hypotheses were formulated and tested using a variety of statistical tests in SPSS (version 26). The statistical tests undertaken included: Cronbach's alpha (to assess internal consistency), Shapiro-Wilk (to test the distribution of the data), a one-sample Wilcoxon signed rank test (testing Hypothesis 1), a Spearman's Rho (testing hypothesis 2), a Kruskal-Wallis test and post-hoc Mann Whitney U test (relevant to hypothesis 3), a one-way Analysis of Variance (ANOVA) and Bonferroni post-hoc test (relevant to hypothesis 4), a Kruskal-Wallis test (testing hypothesis 5), and another one-way ANOVA (testing hypothesis 6). The results of these statistical tests are contained within Chapter 7.

5.7 The Ethics Process and Ethical Considerations

The process of obtaining ethical approval for this study was extensive. The University of South Wales (2019b) deemed the current project as high risk as it was a study which

involved adults with a diagnosed mental health disorder, and because it was a study which required full external ethical approval via the Integrated Research Application System (IRAS). This thorough ethical review process was important to ensure the safety of both participants and the researcher. The researcher completed Good Clinical Practice training run by HCRW to ensure the researcher was aware of ethical consent procedures, essential documentation, and roles and responsibilities in research. This study was approved by both the University of South Wales (USW) (study sponsor) and by the Wales Research Ethics Committee (REC) 1 (see Appendix 19 and 20). A table illustrating the steps taken by the researcher to obtain ethical approval for the current study, with corresponding dates, can be found in Appendix 21. Approval was first sought from the USW Faculty Ethics Committee; the faculty being Life Sciences and Education. They approved the study on the third submission, after amendments were made to the study and study documentation based on the feedback from the reviewers. This then enabled the submission of the IRAS form to Wales REC 1 for review.

Once the IRAS form was submitted, the REC meeting was scheduled for the 6th November 2018. The researcher and Director of Studies attended this meeting and defended the project. Provisional favourable opinion was provided, pending suggested revisions. An additional change was made to the protocol between the REC meeting and the revised submission sent to REC; which was that the researcher would take consent from the service users as where previously this role was to be undertaken by a member of staff working for the health board. Wales REC 1 approved this change, along with the revisions, and granted favourable ethical opinion for the study on the 26th March 2019. Following REC approval being obtained for the study, Health Research Authority (HRA) and Health and Care Research Wales (HCRW) Approval was also attained. All of above-mentioned approvals were submitted to the USW Faculty Ethics Committee for final approval as the sponsor of the study. Once the health board confirmed they had the capacity and capability to support the research, the project was given permission to proceed by the Research Governance Manager at USW. The current study was also considered for adoption onto the HCRW Portfolio, and following review, the project was deemed eligible for inclusion. The HCRW Portfolio is a record of high quality research studies being undertaken in Wales in the subject areas of health and social care (Health and Care Research Wales, 2020).

In addition to the above mentioned process of obtaining ethical approval, a non-substantial amendment was later submitted to the USW Faculty Ethics Committee on the 7th October 2019. The aim of the non-substantial amendment was to increase the opportunity for recruitment of service users. Following approval from the USW Faculty Ethics Committee, the amendment was sent to Health and Care Research Wales for approval. Approval was obtained and the health board confirmed they had no objection to the amendment, and therefore it was implemented.

In order to recruit participants from GP practices, additional funding had to be sought from HCRW to cover the cost of the practices' time. An application for funding for NHS Support Costs was submitted on the 16th October 2019. This funding allowed GP Practices to be paid £28.31 per service user that was identified as eligible for the project; the GP Practice then posted eligible people a participant pack. GP Practices were contacted by the health board's Research and Development Team, and were asked to show an expression of interest if they would like to be involved in recruiting for the current study. Two GP Practices expressed an interest, and later went onto approach people (through post).

Ethical considerations in this project included risk of harm, consent, confidentiality, and debriefing. Smith, Flowers and Larkin (2009) argued that an important starting-point for the undertaking of a research project is the avoidance of harm. The participants in Phase 1 of this study had known mental health issues, and therefore it was important to ensure that harm was avoided/minimised as much as possible. As discussed by Smith, Flowers and Larkin (2009), talking about sensitive issues might constitute harm, and this was considered. The questions created for the interviews were designed specifically for this study, and therefore were not intended to be of an upsetting nature. However, it was acknowledged that participants discussing their experiences of their mental health and the service could evoke distress. Participants were provided with the interview questions in advance so they would have time to consider the questions, and participants were clearly informed that they were allowed to stop the interview at any time. Additionally, service users were provided with the Research Team's contact details, in case they had any concerns about the study. Participants were also provided URL links to relevant organisations should they wish to contact them (Mental Health Foundation, Mind, Hafal, The National Autistic Society, ASD Info Wales, and Autistica).

For Phase 2, there was a risk that after completion of the ASD questionnaire, that staff may become aware of deficiencies in their ASD knowledge, which could be distressing. To address this risk, URL links to relevant organisations (e.g. RCN, GMC, BPS) were provided in the Debrief Sheet (see ASD questionnaire, Appendix 17). Additionally, URL links to organisations such as the Mental Health Foundation, National Autistic Society, ASD Info Wales, and FutureLearn were provided for information and training on ASD. Additionally, possible risk of harm to the researcher was considered. It was ensured that a member of health board staff knew the location of the researcher when individual interviews were being conducted to ensure the safety of the researcher. It was also noted that the researcher may be exposed to distressing topics of conversation (such as previous self-harm/suicide attempts of service users), and that the researcher could discuss any difficulties with the supervision team or Clinical Advisor (a designated healthcare professional working within the health board that supported the research) if necessary. The researcher also undertook Breakaway training at USW; breakaway training provides individuals with skills to protect themselves when threatening situations arise.

The second ethical consideration in this project was the consent process. For Phase 1, it had to be determined that service users had the capacity to consent (this was part of the eligibility criteria). Professionals in the health board, who had been provided with the eligibility criteria, first approached service users about the study. Therefore, recruiters only approached service users who they felt may have the capacity to consent. However, when the researcher met with the service users, it was the researcher responsibility to confirm whether the participant had capacity through discussion of the project. The researcher followed the principles of the *Mental Capacity Act 2005* when confirming participants had capacity to consent. Participants can be considered to have capacity if they can: (1) understand the information relevant to making a decision, (2) retain the information, (3) use or weigh the relevant information as part of the decision-making process, and/or (4) communicate their decision (by any means of communication) (*Mental Capacity Act 2005*). If the researcher believed the participant did have capacity, the researcher completed a Confirmation of Capacity Form (see Appendix 14). The researcher then took informed consent from the service user. For one participant, there had been a significant delay (6 months) between taking consent and the subsequent interview. In this case, capacity was re-evaluated, and

informed consent taken again at the beginning of the interview. For Phase 2 of the project, consent was implied by the mental health professional completing and submitting the questionnaire. Therefore, a consent form was not required.

The third ethical consideration was confidentiality. All data in this project was anonymised. For Phase 1, participants were allocated with a participant number and their name removed. Names of professionals or family members mentioned in the interviews were also removed from the typed transcripts. Service users were informed that confidentiality would only be breached if illegal activity, misconduct, or harm (potential or actual) was disclosed to the researcher. Smith, Flowers and Larkin (2009) stated that it was important to not only obtain informed consent for participants' data collection, but also for likely outcomes of data analysis. This was done for the current project whereby service users consented to their anonymised data and anonymised quotes being used in the PhD thesis, study specific reports, academic journal articles and conference presentations. For Phase 2, participants' names were not required when submitting the ASD questionnaire. Additionally, data collected from the questionnaires was grouped by occupation category, removing the potential identifiability of the participants. All participants (both phases) were told that the researcher would not keep any identifiable information about participants once the study had ended. However, they were informed that the anonymised data obtained in this study would be held by USW for 10 years, and that the data would be stored securely during this period.

The final ethical consideration was debriefing. For both phases, participants were provided with a Debrief Form. For Phase 1, a face-to-face debrief was also undertaken at the end of the interview. As discussed by Braun and Clarke (2013), a debriefing in qualitative research can be seen as an opportunity for participants to ask any questions they might have, and for the researcher to offer a brief overview of the project and provide details of relevant organisations. The Debrief Form for both phases contained a brief overview of the study, the research team's contact details and links to relevant websites.

5.8 Quality in Qualitative Research

Yardley (2000) discussed four principles for determining the quality of a piece of qualitative research. These four principles were termed: sensitivity to context,

commitment and rigour, transparency and coherence, and impact and importance (Yardley, 2000). Brief descriptions of the four principles are provided in the following table.

Table 16: Four principles for assessing quality of qualitative research (based on Yardley, 2000)

Principle	Characteristics of principle
Sensitivity to context	Context of theory: relevant literature and empirical data, appreciating understandings created by previous researchers; awareness of social context, acknowledging participants' perspectives, and consideration of ethical issues.
Commitment and rigour	Prolonged engagement with the topic, development of competence and skill in the methods used, comprehensive data collection, and an analysis that has depth and breadth.
Transparency and coherence	A clear research narrative that is meaningful, a demonstration of 'fit' between the research question(s) and methods/methodology employed, transparent presentation of the research process and analysis, and researcher reflection.
Impact and importance	Utility of the research, theoretical and practical influence, and socio-cultural impact.

Yardley (2000) stated that the above detailed criteria should not be applied rigidly, and the criteria itself is open to flexible interpretation. The four principles can be seen as examples of ways that validity can be encouraged when utilising qualitative research methods (Yardley, 2000). Yardley's (2000) criteria is discussed by Smith, Flowers and Larkin (2009) specifically in relation to IPA, and propose that it is possible that simply choosing IPA as a methodology can show sensitivity to context by the researcher utilising an approach which involves close engagement with a particular homogenous group. When using IPA it is important to use a large number of participant's verbatim quotes to support the themes identified; this will give the participants a voice, demonstrating sensitivity to context. The degree of consideration given to the participants in IPA studies, and the in-depth nature of IPA can be seen to demonstrate commitment and rigour (Smith, Flowers and Larkin, 2009). Transparency and coherence can be evidenced in IPA by clearly describing the research process and by having clear tables demonstrating how themes have emerged from the data set. The

final principle, impact and importance, proposes that research that is valid will share information that can be seen as interesting, important or useful (Smith, Flowers and Larkin, 2009). The current project aims to establish the needs of individuals with co-existing autism and mental health disorder. Knowing the needs of service users in this population could result in better understanding and support; this could be considered interesting, important and useful.

In addition to the four principles discussed above, both PPI and reflexivity can be seen to improve the quality of research. Within the current study, a service user representative was involved in discussions related to the design of Phase 1, and the service user also read all research documentation relevant to Phase 1. Having service user involvement in the design of the study can improve both the quality and relevance of research, and can ensure that research is tailored to the needs of participants (NIHR, 2021). Additionally, reflexivity is regarded as an important way of improving the quality of qualitative research (Smith, 2006). In the current study, the researcher wrote a pre- and post-data collection reflexive statement which made their beliefs, motivations and positions relevant to the research project explicit. Doing this allowed for subtle ways in which bias may affect the research through the researcher's background and beliefs to be acknowledged (Gray, 2018).

5.9 Summary

This study had three aims: (1) to establish the service needs of individuals with co-existing autism and mental health disorder(s), (2) to establish whether these needs were being met by a particular health board based in South Wales, and (3) to assess the knowledge of ASD amongst mental health professionals. Utilising only qualitative or quantitative methods alone would not have sufficiently enabled these aims to be met, and the research questions answered. This chapter discussed the mixed-method methodology underpinning the current project, before discussing the qualitative methodology, IPA, in-depth. Following this, the method for both Phase 1 and Phase 2 were provided including details of participant recruitment, data collection, research procedure and analysis process. Finally, the ethics process undertaken for the current study and ethical considerations were discussed. The following chapter contains the findings for the service users with co-existing autism and mental health disorder(s) who participated in the study. Interpretative

Phenomenological Analysis (IPA) was undertaken on the qualitative data obtained through individual interviews to identify superordinate and subordinate themes.

Chapter Six: Results – Phase 1

6.1 Introduction

This chapter is the first of two results chapters contained within this thesis. This chapter presents the findings of the qualitative analysis undertaken on the service users' interview transcripts. Five superordinate themes were identified from participants' transcripts using Interpretative Phenomenological Analysis (IPA): (1) Experience of Autism Diagnosis, (2) Staff Awareness of Autism, (3) Facilitating Communication, (4) Dissatisfaction, and (5) Making Accommodations. Within each superordinate theme are several subordinate themes. Please see the table below illustrating the themes identified (Table 17). The themes identified during data analysis are discussed in turn within this chapter with participants' quotes provided to support individual themes.

Table 17: Superordinate and subordinate themes from analysis

Experience of Autism Diagnosis	Staff Awareness of Autism	Facilitating Communication	Dissatisfaction	Making Accommodations
▪ Assessment process ▪ Relaying diagnosis ▪ Enlightenment ▪ Post-diagnostic support ▪ Negative impact of late diagnosis	▪ Need for knowledge ▪ Impact of knowledge/ understanding ▪ Masking	▪ Professional-service user interactions ▪ Method of contact ▪ Minimising ambiguity ▪ Disconnection between/within departments	▪ Medication ▪ Reactive not proactive ▪ Waiting times ▪ Acute services ▪ Unclear pathways ▪ Falling through the cracks ▪ Transition to adult services ▪ Broken promises ▪ Gratitude	▪ Environments ▪ A need for consistency ▪ Support preferences ▪ Advocacy

6.2 Theme 1: Experience of Autism Diagnosis

Receiving a diagnosis of autism can be life-changing for an individual, with a diagnosis changing the individual's perception of themselves, often leading to better self-understanding and acceptance (Lewis, 2016). Within this superordinate theme, are 5 subordinates: (1) Assessment process, (2) Relaying diagnosis, (3) Enlightenment, (4) Post-diagnostic support and (5) Negative impact of late diagnosis. These subordinate themes capture the experience of individuals' autism diagnostic journey from the beginning (the assessment process) to the end (post-diagnostic support). The majority

of the participants were diagnosed with autism as adults and therefore, the negative impact upon participants of receiving a diagnosis later in life is also discussed.

6.2.1 Assessment process

Several participants reflected on their experience of the autism assessment process. One recalled his difficulty in finding a professional who would refer him on for autism screening and assessment. He expressed exasperation that he had to fight so hard for an assessment, and that the actual assessment took no longer than an hour. His diagnosis was confirmed the same day.

> *"It was a continuous fight even then to see someone who would eventually refer me to the correct person, who could then diagnose me in a single session of less than one hour".* (Participant 6)

Other participants had slightly different experiences of assessment. One participant met with the assessor twice, once alone and once with one of his parents.

> *"I think I had two meetings with him 'cause obviously I came on my own the first time and then I came back with one of my parents again".* (Participant 19)

Another participant met with their assessor four times, and mentions the completion of numerous questionnaires including a family questionnaire.

> *"I think I met him four times so we had the initial um conversation where he explained the whole process and I asked him at that point do after the first one I said do you do you think that's what it is and he said well I obviously can't diagnose you without going through the entire stuff but he said yeah I think it is so I was like okay um so yep then we went through the different questionnaires, the family questionnaire as well, and he said then I was diagnosed on the back of that".* (Participant 11)

For another participant, she was not even aware that she had undergone the assessment process for autism. This participant had a diagnosis of ASD, but it had not been clearly communicated to her which had left her unsure. Her below quotation illustrate a sense of confusion over the whole process.

> *"I was reading about people looking for a diagnosis and how long it took and how long the assessment was and the waiting lists, so I thought I definitely couldn't*

have been diagnosed now because I didn't go through all the waiting lists, all these long assessments so it didn't all add up". (Participant 3)

This subordinate theme, regarding the assessment process, suggests that there is no consistent assessment process for autism, rather that it is variable based on professional or location.

6.2.2 Relaying diagnosis

Of the participants who discussed their experience of being diagnosed with autism, many suggested that the way the diagnosis had been shared with them was either rushed or very ambiguous. One participant recalled the experience of being told they had autism as impersonal.

"And obviously was told you're autistic, you've got extreme OCD, … that's my time done now, bye bye and it … just felt very, they were very quick and sort of impersonal". (Participant 14)

Another participant described the diagnostic process as being overwhelming; the way the diagnosis was shared with her resulted in her believing that she was a bad person.

*"Quick! Overwhelming! Feeling clueless! Feeling dumb! A bit indignant with the whole empathy situation! I'm just still trying to sort through everything trying to make sense of my life. The *PROFESSIONAL* who did the assessment was nice. I felt like the worst person in the world when he told me what my scores meant on the questionnaires. Being told you fall below the bell curve on an empathy quotient doesn't make you feel great and I apologised to everyone on the home treatment team if I came across as apathetic which may have led them to question ASD but the *PROFESSIONAL* made me feel a bit better when he said that it didn't mean I don't care about people".* (Participant 3)

Several of the participants stated that the way the diagnosis was communicated to them was unclear. After months of wondering if she had been diagnosed with autism, the professional confirmed to her that she had been diagnosed.

"Not in black and white, until in the end I turned around and said to him, well have I got, you know, and he's like, well yeah, you got so many traits that we would say you know, he said there's no definite blood test, I get that but you're either gonna

sort of, put this in place or I'm just like, months I was just wondering well, what's, what's his conclusion". (Participant 4)

"So, no there was no ever, sort of direct, well look we've come to this conclusion". (Participant 4)

Another participant reported a similar experience whereby she believed autism had been a suggestion, rather than a confirmed diagnosis. The process and diagnosis had not been communicated to her explicitly enough as she was unaware she had an official diagnosis of ASD.

"But I think even the report though is still, is quite ambiguous, it did kind of like seem like a light suggestion to my GP, so I assumed if it went to my GP maybe she'd put me forward for an assessment, that's what I assumed". (Participant 3)

Once a diagnosis of ASD was confirmed to her by another professional (as a result of being approached to take part in the current research project), she questioned whether she may have been to blame for not comprehending the information. She proposed a need for better explanation and more resources when sharing an autism diagnosis with individuals.

"Maybe he explained it to me, and I didn't understand it maybe". (Participant 3)

"I would have liked it explained better and maybe more resources, yeah. That could have possibly helped". (Participant 3)

A need for clarity when communicating an autism diagnosis was also highlighted in relation to the participant discussed earlier who was unaware that he had been diagnosed with autism as a child.

"It's kind of difficult to talk about the diagnosis itself because obviously I was that young that I don't even really have a memory of being in the room uh from my parents description of it it was fine it was just it felt as though the doctor was almost pushing for the diagnosis of autism rather than it telling why I would have autism". (Participant 18)

"It's mostly clarity to be honest with you, it's mostly clarity and transparency. So it's nothing particular that I don't like, but I feel as though … with a topic like that it … it shouldn't really beat around the bush with it … it was the assumption that my parents understood what he was trying to put across was, uh, almost in essence their problem because my parents took it one way because he backtracked whereas he thought he put it across okay, so like we mentioned there was just this twenty five year gap where no one was really talking about it". (Participant 18)

Several participants highlighted the way that an autism diagnosis is shared with individuals (and their family members) is not definitive enough. The participants stated that an autism diagnosis should be shared in a way that is unambiguous; this highlights a need for professionals to ensure the diagnosis has been understood. A participant suggested that a way to ensure that people have fully understood their diagnosis is to confirm their diagnosis in writing, i.e. confirm the diagnosis in a letter to the service user. The participant proposed a letter could make the diagnosis clearer for individuals.

*"Like if I'd a black and white, I know it's stupid but, you didn't get a letter to say right you know, if you, my own GP or for the nurse it's like, I assume they had a letter from *PROFESIONAL*? But then if they get a letter, why don't we?"* (Participant 4)

This theme suggests that diagnoses need to be communicated to service users in a way that is both comprehensible and unambiguous. Receiving a diagnosis can change the way an individual sees themselves (Stagg and Belcher, 2019), which suggests a need to communicate diagnoses sensitively.

6.2.3 Enlightenment

Within this theme, enlightenment reflects the change to an individual's identity that is experienced after they receive their autism diagnosis. For the majority of participants, receiving their autism diagnosis was a positive outcome for them. Some participants were at first surprised when they were diagnosed, but still felt like the diagnosis made a positive difference to them.

"It was a surprise when it was first raised that I might be autistic. The tests were then run which showed I was. It made sense when I looked back". (Participant 1)

"So yeah, I think it's, being diagnosed has made a difference. It's helped me maybe not understand myself, but it's made me realise that I wasn't the odd person that I was led to believe I was". (Participant 1)

The above quotation illustrated how receiving an autism diagnosis changed the way the participant viewed herself. The participant indicated that she was seen as different by others, and the autism diagnosis had enabled her to better understand herself. For others, the autism diagnosis answered a lot of questions.

"I'd just had, like the biggest question answered, and … I was quite happy receiving that … help for the autism". (Participant 9)

"My attitude is knowledge is power, I mean if you came from another planet … you'd want to know about it cause it influences everything and that's how I used to feel sometimes, is if I'd come from another planet and like if you constantly questioning why why why why why, yeah so in a way it's freed up head space as well cause I'm not constantly thinking why". (Participant 11)

For some, receiving a diagnosis finally answered life-long questions that people had been asking themselves. Participants were aware of being different and having their autism diagnosis seemed to explain this difference. One participant stated that as well as answering questions they had, the autism diagnosis was a relief to the family.

"Yes. I, felt like it answered a lot of questions, when I was growing up. … My parents were finally relieved that there was an answer … so … it was a big relief really". (Participant 9)

For another, although the diagnosis resonated with her, she did not feel that receiving the autism diagnosis fixed her problems. This indicates a need to support people in a holistic way, rather than by just recognising parts of the individuals, i.e. the autism.

"Granted, so many things make so much more sense now but putting a label on the thing that pushes me into depression doesn't take it away". (Participant 3)

This theme, enlightenment, captured the sense of self-understanding that many participants experienced when they received their autism diagnosis. For many, receiving their autism diagnosis answered life-long questions and allowed them to start

accepting themselves for who they were. It was evident that receiving the diagnosis altered their identity, primarily in a positive way. However, a need to view people holistically was also evident.

6.2.4 Post-diagnostic support

The concept of post-diagnostic support for autism is when newly diagnosed individuals are supported to learn about and manage their condition. Several of the participants reported receiving no support post-diagnosis and felt a sense of abandonment and isolation. Many stated that they were not even signposted to helpful resources.

> *"Cause I've just been given the diagnosis and left … To find it all out myself".* (Participant 15)

> *"Because I've felt I've been feeling alone a lot of it … Struggling by myself, coping by myself, finding out the information by myself".* (Participant 15)

> "*But again there was no follow up information, there was no follow up … after that*". (Participant 14)

> "*Obviously explaining didn't even get offered piles of leaflets even to go through*". (Participant 14)

The participant above stated that he was given no resources to read regarding autism, yet when his children were diagnosed, leaflets had been provided. This suggests a discrepancy between the post-diagnostic support provided to children and adults.

> *"No, nothing at all, there was … obviously with the children we had a pile of leaflets for the children"* (Participant 14)

One participant stated there is a lot of support out there, but he believes people just don't know that the support is even available. This statement highlights the importance of signposting so that individuals can access support that they're entitled to and could benefit from.

> *"There's a lot of … support out there but the majority of people don't even know about it".* (Participant 16)

However, another participant highlighted that for some the cost of transport could be a barrier to accessing support even when signposted.

> *"I was given like a book on diagnosis for adults and it told me about a one stop shop in Cardiff which really wasn't helpful because at the time I was absolutely brassic skint and could not afford the train fare or a bus fare even".* (Participant 11)

A minority of participants reported having positive experiences of post-diagnostic support. One participant was provided with resources and signposted to support and another participant was provided with numerous options post-diagnosis.

> *"Um, yeah … two information books, um, one for me, and one for family members. And then there was all the websites, she listed all the charities, like 21 High Street in Cardiff, places like that. That was really helpful".* (Participant 9)

> *"At the time they gave me I think three options eh... or I could have all of them if I wanted and I chose all of them … they said there's a group in Pontypridd that meets, it's an ASD group so everyone in the group other than the people running it are on the spectrum and it's a social group and I thought that's a bit weird because you know after reading up everything … social group for ASD that seems a bit odd but … that was a thing and then, um, mindfulness which is again is at the Maritime they said that might … be something we can offer so they offered that and also access to *PROFESSIONAL* who still works with me today".* (Participant 6)

Two participants offered suggestions to what support they believed would benefit newly diagnosed individuals. The first suggestion was post-diagnostic counselling to help support individuals to accept their autism diagnosis.

> *"I think when you're first starting out and you're diagnosed I think having counselling to help you deal with it".* (Participant 15)

The second suggestion was to help aid individuals to access the support that is signposted to individuals post-diagnosis. The participant implied that just signposting

alone may not be adequate; service users may need support to access the signposted support also.

> *"So maybe supporting people to go and access these groups for the first time or like … Booking them on the training or think just supporting them with that rather than just handing them the leaflet".* (Participant 16)

This theme discussed participants' experiences of post-diagnostic support. For many, the post-diagnostic support offered was either non-existent or inadequate. Several service users felt isolated after receiving their autism diagnosis, with no support offered to help them come to terms with the changes to their identity due to their new diagnosis. A need for support post-diagnosis was evident in the majority of participant interviews.

6.2.5 Negative impact of late diagnosis

Several of the participants discussed how having a diagnosis later in life had impacted upon them. These participants considered how things could have been different if their autism had been diagnosed earlier.

> *"Had I been diagnosed much, much earlier and it was recognised earlier, maybe that would be different".* (Participant 6)

Some participants believed that not being diagnosed earlier had resulted in them being misunderstood by others.

> *"Cause I feel I've been misunderstood for years".* (Participant 10)

In addition to believing early diagnosis is beneficial for people with autism, one participant highlighted that there are many adults out there who may be unaware they have autism.

> *"Yeah I think the earlier people are diagnosed the better but obviously at the moment there's a lot of adults who haven't been diagnosed".* (Participant 10)

Some participants believed that an earlier diagnosis of autism may have prevented their current mental health difficulties.

> *"Maybe if I'd been picked up autistic at an earlier age I'd have been able to work it through and maybe not have the mental health problems".* (Participant 1)

One participant in the study became aware of his autism diagnosis through being contacted to take part in the current research project; his diagnosis had not been communicated to him or his family previously. This participant believed that if he had been aware of his autism from the point at which the diagnosis was given (age 5), he may have been better able to understand his mental health and may have not required support from services.

> *"I feel as though if myself and my parents had known more about it and known for certain … of my ASD maybe it would … have gotten to the point where I didn't need the mindfulness because I already would have had those coping strategies or I would have understood myself, why I feel the way I do, … why some of my anxieties would manifest in certain ways and how they would affect me, how they would affect my sleep my moods, how they would affect even the way I talk".* (Participant 18)

A sense of frustration was felt by several participants due to the fact that they had been accessing mental health services for many years yet their autism had gone undetected by professionals.

> *"Why did no one pick up on the fact that actually she is coming back through services all the time let's have a look at what's going on underneath that".* (Participant 11)

> *"Uh, CAMHS helped. Um, especially with my anger and, things like that. But I just, like my parents are baffled that I spent so much time with them and they didn't even, consider, um, testing for autism. It's, they still get quite angry about it now".* (Participant 9)

> *"But it's really interesting that they didn't pick up on the autism even though they were watching me in that environment for two and a half hours in a session, and an hour one to one every week".* (Participant 13)

This theme portrays the participants' belief that early diagnosis can enable individuals to be better understood by others, as well as having a better understanding of themselves. This theme speaks of a sense of loss for the life they could have lived if they had received their diagnosis sooner. It was believed by some of the participants

that better self-awareness could have prevented them from developing mental health difficulties later in life.

6.3 Theme 2: Staff Awareness of Autism

Professionals supporting patients with autism need to have an understanding of what autism is, and how it affects individuals with the condition (NICE, 2016). This superordinate theme comprises of three subordinate themes: (1) Need for knowledge, (2) Impact of knowledge/understanding, and (3) Masking. Many participants believed there to be a need for professionals to understand autism, with positive professional-service user encounters often being attributed to the professional having an understanding of autism. Additionally, a need for professionals to be aware of masking in this population was evident to allow for the better detection of individuals with undiagnosed autism.

6.3.1 Need for knowledge

The majority of participants discussed a need for professionals to know and understand what autism is, and how it affects individuals with the condition. The majority of participants deemed the current level of autism knowledge and understanding to be inadequate.

> *"I would want them to understand autism"*. (Participant 7)

> *"They have no clue on autism. They ask you to tell them what do you, what you want them to do".* (Participant 7)

> *"No. I would say no. I don't know how many autistic clients they've got, and to be honest whether or not they recognised it or not, I don't know, but practitioners I've come across haven't really known what autism is and how it affects you".* (Participant 1)

> *"I think more, definitely more awareness, … so like where I've got autism, where I like say I struggle with like eye contact or I struggle with groups it's misinterpreted as like not engaging and it's not that I'm not engaging if I didn't want help I wouldn't be there would I, but you know it's often misinterpreted I suppose".* (Participant 10)

Participants believed there to be only a small minority of professionals who are knowledgeable in relation to autism, with the majority of professionals knowing very little. This suggests that there may be professionals who are specialised in autism, but that the rest of the staff may have very little expertise. In relation to accessing a professional with autism expertise, one participant discussed a time where she was told she would need to access an autism specialist for support, yet was told there was not one available. This highlights a need for more knowledge/expertise of autism in services.

> *"So far as I'm concerned there's only a small few who know and understand my condition, and how it affects my life*". (Participant 7)

> *"Yeah it's polar, it's very polar, they either know a lot or they know nothing*". (Participant 6)

> *"I think they … underestimate how much it affects everything. It's like … it affects the way I communicate, the way I come across, the way they're going to assess me, um, what the results of that assessment might be"*. (Participant 8)

> *"It's something that … I find quite annoying, 'cause when I've … asked about getting some counselling and I've been told that no uh well *ASD ASSESSOR* said that … traditional counselling ain't gonna work very well with me because of the autism and the lack of theory of mind, something like that, … so I said oh well put me through to a specialist, we don't have one".* (Participant 11)

A need for professionals to understand not only autism, but also the relationship between autism and mental health conditions was also contended. Professionals need to be aware of the key characteristics associated with autism to ensure that they are not incorrectly attributed to mental illness. One participant shared an expectation that mental health professionals should at least have an awareness of what autism is due to the field they work in.

> *"And not really understanding how autism and depression interact. … Uh, one thing, uh, I was bagging my Psychiatrist about what people kept writing down in their reports, um, that I was still depressed because, the, my lack of eye contact was a symptom of depression".* (Participant 8)

"For people in the mental health business um you know, there's an expectation that they would know what it is at the very least". (Participant 6)

Several participants highlighted that some professionals held misconceptions about autism, or had knowledge of autism that was simply incorrect. This could lead to inappropriate support being given to individuals with autism. The below participant indicated a need for there to be a more consistent knowledge of autism across the board that is current and appropriate for adults with autism.

"Mental Health Practitioners are not equal in their approach or understanding of ASD. Some have read medical journals and studies into ASD in children and try to apply their book-learned knowledge in the wider field. My experience on the receiving end of such advice is that they have poor understanding and many of the beliefs they hold are simply untrue. Some people try to treat the symptoms, without realising there is an underlying cause. Others have more experience face-to-face with us and are open-minded enough to form their own opinions and admit there is a lot to learn". (Participant 6)

Another participant shared an experience where a professional with autism expertise had to explain what autism was to another professional whose understanding of autism was not factual. Professionals possessing incorrect knowledge or holding misconceived perceptions in relation to autism could lead to frustration and dissatisfaction on the part of the service user, as professionals could be providing support that is not appropriate to the individual's needs.

*"Even with my own *PROFESSIONAL* she said she would fix me in a couple of months, she'd have me travel trained and cooking and going out and about, *ANOTHER PROFESSIONAL* had to step in and tell her it doesn't work that way".* (Participant 7)

Another contended reason for professionals needing a working knowledge of autism is so that they can help identify individuals who may have autism but are currently unaware/undiagnosed. The majority of participants in this study were diagnosed as adults, and a need for early identification of autism was evident.

"I think more awareness across like all services but the fact that some people haven't got a diagnosis of autism but they could still be struggling with it". (Participant 10)

In relation to knowledge of autism, one participant stated that lacking knowledge of autism was not isolated to professionals, but rather a societal issue. This statement indicates a need for more awareness of autism for all.

"I don't know if the knowledge of autistic spectrum conditions is as high as might be desirable really, but then that is not unique to health practitioners, that's just a ... a broader thing within society". (Participant 19)

The majority of participants believed that professionals did not have an adequate knowledge/understanding of autism. However, several participants specifically discussed the autism knowledge held by General Practitioners (GPs). As a point of entry for an autism diagnosis, GPs have a role in referring participants for further autism assessment. Therefore, there appears to be a need for GPs to have an awareness of autism so that they can judge whether patients need further referral. However, the below quotations indicate that GPs may not have the autism knowledge/training required to be gatekeepers to diagnosis.

"There are so many points of failure. Right from the get-go, getting a diagnosis is difficult and frustrating, with GPs lacking in training or specialist knowledge and without a clue who to refer one to". (Participant 6)

"*Obviously once I'd spent the three and a half hours literally with the GP cause apparently I can make fabulous eye contact I'm quite witty and quite flirtatious can't be autistic um all the sort of that classic sort of thing that autistic people can't do um so after that that was the longest period was actually in engaging with … her to persuade her for the diagnosis"*. (Participant 14)

Several participants specifically discussed training as a means of improving the autism knowledge of professionals. Participants argued the importance of autism training and contended that currently the education is just not there. A need for training to convey to professionals the diversity of the autism spectrum was also highlighted.

"Training is so important um you know there needs to be more understanding and education when it comes to dealing with people with autism". (Participant 6)

"The education isn't there they're not … being educated in what it is and what it needs". (Participant 6)

"I had to explain the meaning of the word 'spectrum' to them, as they assumed everyone to have an equal need". (Participant 6)

"I mean it's like a buffet with autism, isn't it? … Um, you load up on the chips, you get a little bit of salad, but yet somebody goes in and gets all the salad and has 2 chips. And that's how it is with autism. You, so that, you can train them on what's in the buffet, and then you can say some people will have more, some people will have less, some people may have one or two of these, some people may have all of them. … 'Cause every … person with autism is different, it's not an excuse not to try and understand autism". (Participant 8)

A need for autism training to be universal and standardised was also highlighted. One participant contended that he never knows if the professionals (specifically GPs) he meets will have any knowledge of autism or not. Also in relation to GPs, another participant believed the training they have is not enough and that the knowledge they have is perhaps more relevant to children with autism rather than adults. One participant proposed that all professionals who play a role in supporting people with autism should have completed autism training.

"The training is not universal so it all depends on who you talk to um you walk into the GP's office you've no idea whether the person you're talking too has even heard of autism or whether they're just nodding and smiling and you know". (Participant 6)

"The GP is kinda of like overloaded and they don't really understand what you're doing cause they probably get like a day on it, on autism, but it's a child, you see what I mean it's like there's so many gaps". (Participant 2)

"Then we need some method of initial access to diagnosis and training for any and all staff critical to assisting us". (Participant 6)

This theme evidences a need for professionals to have some knowledge of what autism is, and how it affects the lives of individuals with the condition. The majority of participants believed that professionals' current knowledge of autism was insufficient and shared a desire for this to change. A need to change incorrect misconceptions held about autism was highlighted, as well as an expectation that mental health professionals should have at least a basic understanding of autism. A need for GPs to have a better awareness of autism was specifically noted due to GPs being a point of entry for individuals who would like to pursue a diagnosis. Finally, training was discussed as a means to improve professionals' knowledge of autism.

6.3.2 Impact of knowledge/understanding

During the interviews, participants discussed numerous professional-service user interactions, some negative and some positive, and many times the outcome of the interaction seemed to be dependent on whether the service users believed that the professional had knowledge of autism. This indicates the importance of professionals having adequate autism knowledge, and illustrates how having autism knowledge can improve interactions with service users. Participants stated that autism knowledge would allow for the better detection of undiagnosed adults with autism and could stop service users' difficulties being wrongly attributed to mental health conditions rather than autism.

> *"If they know like the certain signs like they got a patient who really struggles with eye contact uh you know maybe doesn't like the lights on or something you know would be a good idea if they could have like maybe warning signs … So they could say maybe this persons on the spectrum and just do one of those like an autism questionnaire and then see if it's worth looking into further".* (Participant 10)

> *"Well to be honest Chelsea, I had problems for years. Umm, I think my problems were more classed as mental health 'cause nobody knew about my autism".* (Participant 1)

For some there was a frustration that professionals didn't understand them; they believed that professionals didn't understand the toll of having co-existing autism and mental health on the individual, and this could impact on the patient-professional relationship. One participant discussed an encounter with a GP that he believed was

lacking in autism knowledge. It was suggested by the participant that the GP chose to deal with the depressive symptoms that he was experiencing, rather than the (at that time) undiagnosed autism as the GP knew how to deal with depression (e.g. prescribe anti-depressants). This situation suggests that professionals, when not knowledgeable in autism, may choose to deal with symptoms they feel more confident in treating (e.g. low mood). This could suggest that having autism knowledge could make professionals more confident to support service users presenting with autism.

> "*It's like they haven't grasped the impact of what it actually means to have autism and mental health, they don't understand it".* (Participant 2)

> *"Mine [My GP] refused to deal with my questions pertaining to Autism, preferring to treat depression and depressive symptoms, which they had at least heard of. Unfortunately, their medication route took many months of trial and error, made my life extremely difficult and ended up putting me in hospital".* (Participant 6)

Several participants recalled encounters with professionals who were knowledgeable about autism; this led to the participants feeling understood and valued. The below quotations evidenced encounters where the clinician had put their knowledge into practice which had resulted in a positive experience for the participant. One participant recalled receiving a letter from a professional who had put a photograph of herself on it. This act confirmed to the service user that the professional understood autism. The professional had adapted her practice to suit the needs of people with autism, as many individuals with autism dislike uncertainty and having the professional's photograph in advance could help to alleviate the service users' anxiety.

> *"Well for me personally it made me realise that she actually knows autism, that was the key for me. It was not safer, it was the fact she totally puts her knowledge where her mouth is kind of thing, putting it bluntly. She, cause I thought cause she's obviously knows what she's doing cause she put a photograph, and that's when I was reassured that she's great".* (Participant 2)

> *"I wasn't in a good way when I went there and I couldn't suppress anything, I was clicking my keys, my foot was going and she didn't once ask me to stop doing those things which I've been met with a lot, and she told me that I could book my*

appointment ahead which isn't normally how you do it. She told me the quietest times to book my appointment". (Participant 3)

"She personally booked the next appointment with her, on her computer screen. …And put me in the last appointment where the waiting room is quiet, where I didn't have a 10 minute slot, ... she gave so much of her time to me". (Participant 4)

This subordinate theme conveyed the belief of service users that professionals having knowledge of autism is beneficial, and that having autism knowledge can lead to more positive interactions with professionals. Service users suggested that autism knowledge in professionals can allow for undiagnosed individuals with autism to be better detected in services and for autism presentations to be better understood by professionals. Both negative and positive service user experiences were discussed which illustrated the way professionals' level of autism knowledge could impact upon service users' experiences in services.

6.3.3 Masking

As mentioned previously in this thesis, masking is a component of camouflaging whereby an individual with autism conceals their social communication difficulties from others (Lai et al., 2017). Several participants discussed masking in the context of interacting with mental health professionals.

"You're automatically masking when you're in an appointment". (Participant 13)

"And of course obviously I mask really well so … face to face I come over as being really happy, smiley, you know quite level head[ed] you know, actually that's my defence mechanism, and [the] more stressed [I am] … the more I smile so sometimes they're not getting a clear picture as well". (Participant 14)

The above quotations evidenced how service users can mask when in appointments with professionals, and how the participants' use of masking could potentially lead to difficulties being missed. The above quotations suggest that there could be incongruence between the way an individual with autism presents and their underlying emotional state. Other participants discussed the implications of masking such as how

difficult it can be to drop the mask and how masking can hide characteristics of autism, potentially resulting in late diagnosis for service users if professionals are not aware.

> *"Cause bearing in mind autistic people have worked quite hard usually at masking conforming to social expectations to avoid their issues … and it's not an instinct that's lost easily".* (Participant 10)

> *"so we end up hiding it and you know if it's diagnosed so late you've got to be able to see through that you've got to understand that the person coming in does not want you to see them as different".* (Participant 6)

Another participant contended that masking can actually impact upon an individual's wellbeing due to the amount of energy that it requires to maintain.

> *"masking is one of the … biggest problem, I guess, that we have is that we spend most of our energy masking the problem so that we can fit in so that we can communicate, um, and then the energy that we're left with is not enough to cope".* (Participant 6)

The importance of professionals having awareness of masking is evidenced by the below participant who discussed a positive experience with a professional who was able to identify their autism despite the mask. The participant believed he was 'lucky' to come across a professional with this knowledge, which suggests that professionals having this knowledge is not common in services.

> *"Somebody who identified um the problem despite the mask … They saw through that and was just like well yeah you know we can ask the right questions, we can have the right conversation and we can see that that's how it works".* (Participant 6)

> *"Yeah so to have somebody who just bypassed that and was completely open to it who understood, it was … unique … I think that's the only person that I've spoken to with that level of understanding uh and yes I was lucky to find somebody who was that well trained".* (Participant 6)

This subordinate theme, masking, portrays a need for professionals to have an awareness of how masking contributes to camouflaging in autism. It is contended that

this knowledge could result in better experiences for service users with autism and could allow for better detection of individuals with undiagnosed autism.

6.4 Theme 3: Facilitating Communication

This superordinate theme aimed to identify ways in which communication could be used most effectively to benefit the service user experience. Within this theme are four subordinate themes: (1) Professional-service user interactions, (2) Method of contact, (3) Minimising ambiguity, and (4) Disconnection between/within departments. Negative interactions between the service and service users can result in anxiety for service users and can sometimes deter service users from turning to the service in times of need. This illustrates the need for successful communication between mental health services and service users. Additionally, a need to have effective communication between/within the service is discussed.

6.4.1 Professional-service user interactions

As part of their interviews, all participants shared their experiences of professional-service user interactions during their time accessing services, some negative and some positive. Several participants stated they needed someone to talk to, someone to offload to, and they felt mental health professionals played a role in this. Participants discussed the benefit of discussing their feelings with professionals and highlighted the negative consequences of bottling-up or suppressing their feelings.

> *"So it was somebody to offload to, so that sort of helped as well. Because it's not just the case of sitting there on medication, you need to talk".* (Participant 1)

> *"I just wanna talk to somebody. … I often, … blow things, ya know as somebody on the spectrum, things are often bigger in my head, so it often helps to have an outside perspective that isn't family or a friend".* (Participant 5)

> *"It is beneficial to discuss your moods/feelings with a mental health practitioner".* (Participant 1)

> *"I call that suppression city and I can only do it for so long before um my brain explodes".* (Participant 12)

The need for professionals to listen to what service users are telling them was also present within the transcripts. Participants stressed the importance of professionals

listening rather than assuming, and also stressed the importance (especially with the current population) of listening to the content of what the service user is saying rather than the tone in which it is being said. Participants suggested that it is also important to not dictate what a service user must do but rather provide options and work collaboratively.

> *"So long as I feel like I'm being listened too and not being dismissed that would probably be enough for me".* (Participant 18)

> *"I don't want you to dictate to me I want you to tell me what to do so that I can go oh yeah that works for me that doesn't work and we can work together then to see what works for me so I think more than anything is for people to work together to listen to what the people are saying to actually believe them".* (Participant 13)

> *"I dislike it when others presume to know me and my needs. This can occur when contacting the Crisis Team and speak to ones who don't know me. They listen to the tone and timbre of my voice not what I'm saying".* (Participant 1)

A need for professionals to communicate with service users in a clear and direct manner was discussed by participants. Participants conveyed that they would prefer professionals to get straight to the point without engaging in small talk. The participants meet with professionals for a purpose and would like for that purpose to be addressed during the appointment.

> *"So long as there's transparency and clarity and so long as there's I feel as though I'm being listened too and taken seriously that would be fine".* (Participant 18)

> *"It's like they don't necessarily try to engage in chatting about things that I'm just like oh no and you know they get straight to the point with things*". (Participant 11)

> *"You know I'm here for this I was told this needed to be done let's get it done".* (Participant 19)

Participants discussed a variety of professionals' characteristics that seemed to contribute towards service users having positive experiences, e.g. being kind, caring, friendly, approachable, attentive, authentic and compassionate. These characteristics were all associated with positive interactions with staff members. Professionals who

conveyed these characteristics in their practice made service users feel valued and comforted which improved rapport.

> *"She said that she really enjoyed working with me and she thought I was fascinating and she was really kind and I thought that was really nice, and made me feel like, you know, she made me feel like I was interesting so, that made me feel really good".* (Participant 2)

> *"Um, I am pretty cautious about meeting new people, so it's really comforting when they're really, like caring and really friendly and approachable".* (Participant 9)

> *"They're amazing they are very attentive very patient very soft spoken".* (Participant 12)

> *"I keep going back to kind of the people, the nice people, the genuine people, that like makes it a little bit better. I think it makes all the difference".* (Participant 3)

> *"I guess I met decent people, compared to some people I've met who made me feel worse. So when you do meet people who genuinely care and show compassion, it does make a difference compared to what you're used to".* (Participant 3)

However, one participant highlighted that the intentions of the professional can also have an impact. As the participant highlights below, the professional may not fully understand the service user's difficulties but he always entered the appointments with good intentions and tried his best to support the service user. Therefore, understanding as well as good intentions are valued by service users.

> *"He's good, I feel that he doesn't understand, but he still tries his best … and I think that's all I really want from a doctor".* (Participant 20)

However, several participants shared interactions with professionals that had been negative. The participants stated that the way they were spoken to by professionals had a negative impact, e.g. made them feel intimidated or caused longer-lasting distress. Additionally, one participant recalled a negative interaction which then resulted in her not wanting to see the professional again. This suggests that negative interactions could deter individuals from seeking help when they need it in the future.

"I've had them mostly snap at me rather than shout but um it's quite intimidating". (Participant 12)

"They don't seem to comprehend that the way they talk to me is very stressful". (Participant 12)

"But you're kind of afraid to go back because of last time with the psychiatrist, where you felt like you were doing everything wrong and not, you were failing at taking medications, so...". (Participant 3)

This subordinate theme illustrates the importance of successful communication between professionals and service users. Service users highlighted a need to talk as a means to offload, a want to be listened to by professionals, and a need for clear and direct communication. Examples of professional characteristics that contribute to successful professional-service user interactions were provided. The importance of successful interactions was evidenced by the fact that negative interactions can deter service users from help-seeking in the future.

6.4.2 Method of contact

When participants were asked their preferred method of contact for the health board, the majority of participants possessed a strong dislike for phone calls. Most participants preferred for contact to be in writing, so they had time to digest the information and consider a response. Participants found phone calls, particularly calls which were not pre-arranged, very stressful. Some participants stated they found it almost impossible to talk on the phone to someone, especially someone they do not know.

"Cause the ASD, yeah the ASD and social anxiety, it's more or less impossible to talk on the phone with someone I don't know". (Participant 7)

"I don't mind a phone call but if it's like if I ain't planned for it and all that … can set my anxieties off". (Participant 16)

"It's again, it's depending on the day because if I'm … having one of my off days, I wouldn't even answer the phone". (Participant 16)

Some participants further elaborated on their difficulties with undertaking phone calls. One participant found the to-and-fro nature of communication more difficult on the phone leading to anxiety. Another participant found sharing personal information with a stranger over the phone anxiety-provoking; the participant prefers to communicate by written means so that he can write a reply and revise it if needed before responding.

> *"Phone … I bet everyone says that don't they like I can do the phone but I don't like it at all … knowing when it's like your turn to speak or you know sometimes I come across like I'm interrupting people but what it's like its … But what usually happens is like they're talking about something and they stop to think and I think they've finished talking … And then I start asking questions or saying something and it's don't interrupt me oops sorry didn't mean it".* (Participant 10)

> *"It's easier to talk on the phone when it's not personally me … that I'm talking about. I find that incredibly stressful uh, I get very anxious talking to people on the phone if I don't know who they are and that I'm giving them you know personal information uh, I tend to avoid it if at all possible and would prefer, I prefer email … um that's my, that's my go to because with an email you can put your thoughts on the page and if you don't like what you've written, if you think well that's you know, maybe that could be misinterpreted, maybe that's, that's not what I'm trying to say or maybe there's something I haven't said … often on the phone I'll, I'll become anxious and then I won't say what I want to say and then after I put the phone down I'll think I should have said this, I should have said that, why didn't I say these things and you know email gives you the opportunity to you know to check it".* (Participant 6)

One participant contended that for those unable to call or respond to calls from the health board, there should be an alternative method of contact offered. The participant suggested that there should be a facility for service users to text in (or maybe email) rather than call as service users may not always have someone who is able to call for them. Another participant discussed difficulties his mother encountered when she made calls on his behalf; he recalled staff members refusing to speak with his mother due to him being over 18 years of age. The participant expressed frustration at this, and attributed this to a lack of autism understanding by staff members. The below quotations evidence a need for alternative methods of contact than phone calls alone.

"The first one of course is able to use email, or text, or some, it wouldn't be beyond the wit of man to put a phone, to put a mobile phone in reception would it? …And that people text in to say I can't make my appointment. … Um, because the onus is on you to phone. … And there's always the assumption that there's someone there who can do it for you". (Participant 8)

"As I find it distressful to talk to people I don't know, my mother does the phoning and she's told, She's told that they, they cannot speak to her as I'm an adult, autism, learning difficulties, which bit don't they understand?" (Participant 7)

In addition to participants having difficulties with phone calls, some participants stated that they would not answer phone calls from a withheld number or a number they are not familiar with. Most health board calls appear as withheld numbers to service users, and this could result in service users missing important calls relevant to their care. Having an alternative method of contact could help to alleviate this contact barrier.

"They ring off withheld numbers which I don't answer, I never answer withheld". (Participant 10)

"I don't answer calls from withheld numbers and I don't answer calls from numbers I don't recognise". (Participant 19)

Additionally, a need for multiple forms of communication in relation to appointments was expressed by some participants. Some of the participants recalled missing appointments in the past due to not being aware they even had an appointment scheduled; this could lead to service users being inappropriately discharged from services and wasted clinician time. One participant proposed that a letter should be sent for an appointment, followed by a text reminder closer to the appointment date to ensure patients do not forget/miss their appointment.

"I wouldn't like just the one. The be all and end all. I would like multiple forms of communication because everything gets lost". (Participant 5)

"Yeah. I like to have a letter, I keep all of my appointment letters, they're still ... I like that, but then, having the text reminder, 'cause the GP gives the automatic alert two days before ... so it's like, oh yeah, don't forget". (Participant 4)

This subordinate theme highlighted the desire for this population to be contacted via written means (i.e. letter, email and text) rather than by phone call. The majority of participants found phone calls to be highly anxiety-provoking, with some participants stating they are unable to use phone calls as a means to communicate. The issue of withheld calls from the health board was raised, as well as a desire for at least two methods of communication in relation to mental health appointments. Contacting service users with autism via written means could help to alleviate unnecessary anxiety.

6.4.3 Minimising ambiguity

The majority of participants indicated they disliked uncertainty and/or ambiguity. A need for information, and to feel informed, was important to the participants; not knowing what was going on in relation to their care/support was anxiety-provoking for them. Participants suggested that better organisation, and information being explained more clearly, could help to reduce the ambiguity and subsequent anxiety.

> *"No, autistic people like to know what, a little bit about what's going on and have a rough idea, and you know when I was like sort of in limbo and I didn't know what was going on and that kind of didn't help with the … anxiety, lack of organisation and you know it, it didn't help".* (Participant 10)

> *"But from experience maybe having things explained more clearly, maybe less ambiguity where appointments are concerned".* (Participant 3)

Several participants expressed a desire, where possible, for information to be shared with them in advance. This would help to reduce participants' anxiety prior to and during appointments and would give them time to prepare for the appointment. Participants highlighted that they would like to know the following information in advance of any appointment: date and time (particularly relevant to home visits), location of appointment, what professional(s) the service user will be seeing, the professional's role, and the duration of the appointment. Several participants also indicated they would like to know what the professional looks like in advance, with one participant suggesting that photographs of professionals could be displayed in waiting rooms along with their name and job title.

"I'd say location, time, and a description of the person I'm looking out for". (Participant 7)

"But I guess again that was because you don't know who's coming, when they're gonna go, how many people there's gonna be, if you've met them before, you know". (Participant 3)

"Well if I'm meeting that person then, if I'm meeting that person then maybe, maybe just a, maybe just a photo of what they look like". (Participant 7)

In addition to the above information, some participants highlighted a desire to know what the appointment was for and what would be discussed in the appointment. One participant stated he would like this at least 3 days in advance to allow him time to prepare for the appointment. Another participant shared an experience which resulted in her feeling completely overwhelmed; she had met with a professional new to her and was asked questions she was not prepared for. Providing a proposed itinerary for the session to the service user in advance could help to alleviate anxiety and distress to the person. Additionally, it was suggested that professionals should inform service users of approximately how many sessions they will receive as this could affect how much service users disclose.

"I'd say just, yeah. I'd say I would like to know what, like what, like what the appointment was for. So that, and tell you at least, at least 3 days from then". (Participant 7)

"But then, turning up and speaking to her, she's asking questions that I just was not expecting, I … totally flipped". (Participant 4)

"I don't know, it's that not knowing. And you get to the point where, you, are about to say something, and think well if I haven't got another appointment, I don't really wanna open up this". (Participant 4)

Many participants conveyed frustrations at waiting times/lists, but within that frustration was a desire for participants to be informed about their progress on waiting lists. Participants discussed being on waiting lists for months and receiving no updates from the service. The below participant discussed a time where she thought she had been discharged from mental health services as she had not received any updates from

them. The participant expressed a need for service users to be updated on their position on the waiting list, which would result in them feeling more informed and reduce worry.

> *"They don't keep me informed of what's going on so they could at least write a letter saying just say oh I've uh you know you've got x amount of months to wait you know but you are on the waiting list and maybe just send us an update here and there saying like oh you've moved up the waiting list now and you've only got this amount to wait you know just keep us informed I think would be a would be a good idea".* (Participant 10)

The current subordinate theme suggests a relationship between ambiguity and anxiety, whereby higher ambiguity can lead to heightened anxiety for service users. A need for service users to feel informed in relation to many aspects of their care was discussed, e.g. when and where their appointments are, what professional they will be seeing, what will be discussed, and how long the intervention will last. Additionally, participants expressed a desire to be updated when on waiting lists to help reassure them that progress is being made and to offer provisional timescales. Participants conveyed a need to have the required information in advance so that they had adequate time to prepare for appointments, which could result in better professional-service user interactions due to lower anxiety levels.

6.4.4 Disconnection between/within departments

A subordinate theme that was prevalent within transcripts was a disconnect between different teams and departments. This disconnection often led to the service users feeling frustrated and/or exasperated. Participants recalled times when they had attended appointments and the team were unaware why they were being seen, and times where they arrived at the appointment and it was unclear which professional was even seeing the participant. Another participant discussed a time she had been to the Crisis Team who had signposted her to her GP. The participant recalls the dread of having to repeat everything she had discussed with the Crisis Team; this repetition could be reduced, and distress relieved for the service user, if the Crisis Team directly communicated with GPs.

> "*Basically we don't know why you've been referred to me*". (Participant 8)

"*But it's often quite complex about who I've got to see, when I'm seeing them, and then they'll often get in arguments with each other about who I'm supposed to see. So I have to wait about 15 minutes for them to sort it out, who the hell I'm supposed to be seeing*". (Participant 5)

"*I was like right, you've gotta go see your GP now, so whatever you've discussed here, or whatever they've took, you've gotta then go and tell your GP"*. (Participant 4)

Other participants discussed a need for better connection between certain services. For example, one participant highlighted a need for increased communication between professionals in primary and secondary mental health services. The participant suggested that expertise from professionals in secondary services could be sought to better support service users in primary mental health services. Another participant recalled a time she had a stay on an inpatient mental health ward, and professionals on the ward were unaware that she had autism. The participant expressed frustration at staff members not being informed of her diagnosis, and this could have impacted on the care that she received.

"I think the problem is perhaps lack of awareness, so maybe a bit more communication between like primary and secondary care or … at least with the … people who work with autistic people as well, maybe primary care could communicate more with them … You know to see like what can we do to help this autistic person who struggles with you know sensory issues what would you suggest or you know that kind of thing". (Participant 10)

"Cause when I was in hospital, um, back in October, I took a patient passport in, and I was saying to someone oh yeah cause being autistic, and they were like you're autistic?... and I was like yeah, my name is…..well don't you hand it over then? Well yes, I said so why are people acting surprised when I tell them I am?" (Participant 1)

A further example of disconnection was discussed in relation to a lack of communication between A&E and the Crisis Team. As some service users with mental health difficulties may self-harm/attempt suicide and require support from the Crisis

Team, there appears to be an immediate need for these two services to be closely connected.

> *"When I was suffering from extreme low moods, um, there was an incidence where I went to A&E, um, and we waited for, I think, it was about 10 hours, just for them to tell us that we could have gone round to the mental health side".* (Participant 9)

This subordinate theme indicates a disconnect between/within departments that could result in frustration for service users. A need for diagnoses to be communicated to staff members who will be supporting service users was evident as well as a suggestion for better communication between teams (such as the Crisis Team and GP) to reduce distress for the service user. Additionally, one participant suggested the benefit of primary mental health teams sourcing expertise knowledge from secondary mental health teams to benefit service users.

6.5 Theme 4: Dissatisfaction

This superordinate theme conveys aspects of the adult mental health service that service users are not fully satisfied with. Within this theme are nine subordinate themes: (1) Medication, (2) Reactive not proactive, (3) Waiting times, (4) Acute services, (5) Unclear pathways, (6) Falling through the cracks, (7) Transition to adult services, (8) Broken promises, and (9) Gratitude. The final subordinate theme, Gratitude, captures how grateful participants are for the support they have received from mental health services, even though they acknowledge that the service has room for improvement. Identifying areas in which service users are less satisfied may enable services to target these areas with the goal of improving service users' experiences in the future.

6.5.1 Medication

The majority of participants in the study expressed frustration in relation to medication. Several participants felt professionals' only/main priority was to medicate them rather than address the underlying difficulties they were experiencing. Participants used phrases such as "fobbing us off" and "palming me off", illustrating how the way medication is discussed and prescribed to service users results in them feeling unimportant and devalued. Some participants conveyed a resistance to being

medicated, whereas other participants acknowledged they needed some form of medication but did not like the importance placed on medication rather than other support options (e.g. talking therapies). One participant highlighted they would prefer to be taught "skills" to better deal with their difficulties rather than being given "pills". This quote portrayed a desire of the service user to manage her own difficulties; however, she felt she needed support from mental health services to be able to learn the coping strategies and skills required to do so.

> *"I just get medicated really".* (Participant 15)

> *"I just don't feel that psychiatrists listen, unless you kind of like wanna take what they wanna … give you, they don't really take anything into consideration".* (Participant 3)

> *"They're fobbing us off with medication that is for people with mental health, and then, and then they're giving me Fluoxetine which is keeping me sedate but it isn't resolving my problem, so whatever my problem is all I want is some counselling, but I'm not, but it's like I'm asking for masses of amounts".* (Participant 2)

> *"Stop trying to throw medication at me, you know I've said before it's skills not pills you know … I want, I really object to this tendency of what do you want a diagnosis for if you don't want medication for it"*. (Participant 13)

> *"Why didn't they notice that maybe something was different instead of just palming me off with medication … I'm not saying I don't need medication. But that was their sole aim ya know? … Was get a review, get her medication changed".* (Participant 1)

Several participants recalled negative encounters with professionals in relation to medication. One participant recalled a time she was being trialled on a new medication that did not agree with her and the professional did not listen to her when she expressed her concerns. Another participant recalled a professional experimenting with his medication when he was happy on the medication he was originally on. He felt the medication he had been prescribed was inappropriate (as he did not have Bipolar) and caused numerous side effects. Both of the below experiences imply that the professionals did not include the service users in decisions about their medications and were not listening to concerns they were voicing in relation to side effects.

"The lady said I'll reduce it from 30 down to 20. But I thought that's not solving the problem you're just taking it down, but I'm still gonna be, but I'm more iller on it than I was when I wasn't cause I'm shaking now, I'm sick, I can't stand up, my brain is swelling and you're telling me that this is okay, and you'll just get over it after the side effects pass. And I thought how'm I gonna get through the side effects, I like a little bit of life where you can get up and, and sort of communicate with people, with this I'm a zombie, I'm actually really ill and I'm scared, because I can feel my brain swelling, I've never felt that feeling before". (Participant 2)

"I was having problems and they decided … when I went up to um, adult mental health they'd change my meds to a very strong bipolar med, which was uh uh, and they were telling me oh you might have bipolar and stuff like that, and like they were putting me on these meds that you're meant to treat people with serious bipolar, it was like an 8mg Olanzapine and stuff, so I lost, I started losing my hair and I put on a lot of weight and … I always had a really fast metabolism and I just and they act, one of the symptoms of the meds was like weight gain and I put on like loads … and that's with the binge eating problem started an all and I eventually came off them and demanded that I go back on my … original dose of Risperidone". (Participant 17)

A smaller number of participants shared positive experiences in relation to medication. For some the professional had involved the service user in decisions relevant to their medication and did not force them to change their medication (type of medication or dose) against their wishes. The below quotations evidence the importance of listening to service users and providing them with autonomy in relation to their treatment.

"He converses with me like he said now you know do you think your medication is okay or do you think I need to increase it, well that gives me the choices which I like and I said no I'm happy on what I've got, I don't want to increase it. Whereas, others in the past have chopped and changed, increased, ya know, and it's left me in sort of like a medication stupor". (Participant 1)

"He always has the right advice, he doesn't try and force me to change my meds, he says I'll keep your dose whatever you're comfortable with". (Participant 17)

This subordinate theme portrayed difficulties service users experienced in relation to medication. For many, the importance placed solely on medication was frustrating.

Some participants acknowledged the need for medication, but suggested they need additional support such as counselling. Both positive and negative experiences of medication reviews with professionals were discussed. The outcome of the medication reviews seemed to be affected by whether or not the service user felt the professional was listening and involved them in medication decisions. A need to listen to the wishes of service users to collaboratively decide on appropriate medication was implied.

6.5.2 Reactive not proactive

This theme contends that AMHS are reactive rather than proactive. In other words, the service reacts quickly when patients are very unwell (in crisis) but do not work actively to prevent service users' mental health declining. The below participants reflected on just how unwell they had to become, being actively suicidal, before mental health services paid attention to them. The one participant highlighted that by that point, she didn't want them to try to save her, illustrating just how hopeless she felt at that time.

> *"It literally took my suicide attempt to get them to notice who I was".* (Participant 5)

> *"I'm very aware of just how unwell I had to be to get it, that it wasn't I could go to them and go I'm not functioning something's wrong something's not right and … it get ignored, and it didn't matter how much pain I was in it get ignored, and it wasn't 'til I was at that point of actually I don't want to be here and I was trying to consistently take my own life the people would take me … seriously and by, by that point I actually don't want them to do anything".* (Participant 13)

Several participants argued that individuals should not need to get to crisis point before they can receive support; participants believed they should be able to access support as soon as they start struggling to prevent them reaching crisis point. It was argued that crises could potentially be avoided if service users were adequately supported.

> *"But if it gets to a desperate point, you sort of like got A&E or a crisis team … it shouldn't need to get that far".* (Participant 15)

> *"That's a hell of a long time to wait and things shouldn't have to escalate to be able to get help should they … You know once you start struggling, you should be able to have, just get in and sort it out … 'cause like you wouldn't have to wait until*

the cancers nearly killed you to get treatment because they want you to get treated earlier, mental health should be treated in the same way". (Participant 10)

"I find the fact that when I go in a crisis then obviously that could technically be avoided with more contact, so again it's … about more, more contact but I do understand obviously that … I'm not the only person out there with problems". (Participant 14)

"They're now saying, they're now covering their ears as if they can't, I don't exist, until one day I end up having a breakdown and then, and only then, will they pick me back up again, but then they say, but until then they're not preventing it, they're just allowing something to happen". (Participant 2)

"But again it's one of those things where they'll put out the main fire but they'll leave it smouldering". (Participant 13)

It was argued that there is a need for support to be proactive, rather than reactive; one participant referred to support as being all or nothing. It was suggested that the way mental health support is currently provided results in a vicious cycle whereby an individual has a crisis, reactive support is provided to stabilise the person, all support is then withdrawn and then the person experiences another crisis, and so on. Support being available when required might prevent service users' mental health from declining and reaching crisis point again.

"Again the lack of the joined up thinking, the lack of ongoing monitoring is kind of you're in you're out and then see you later until you have your next crash". (Participant 11)

"Yeah I felt that they were generally top of their game when they were with me, and they were doing exactly what was perfect, it's just when they've gone, there's no one there". (Participant 2)

"Yes absolutely, just maintenance, absolutely, you got the nail on the head, maintenance, we'll wait 'til you go to one extreme the breakdown, and then bringing you up, bringing you up the services and being there step by step then going 'off you go' and suddenly left again, and then you fall back again. You go

back into the services right at the bottom in the bed, and then back again you get all the support and then you let go, 'off you go' and then back round we go in a circle. I bet if you asked most people in mental health that's what happens to them, they get the attention as it were, and then they end up back in the system getting all the attention, then once they feel, they fly, off you go and they go back in and they fall back down again, and so the spiral goes round". (Participant 2)

"Obviously because there's only an annual check um unless I go into crisis which, which only happened once um in the last couple of years, then I obviously get referred back in but it's sort of obviously you get seen you get sort of referred out you get signed off and you get back in for the annual and it's, it's no sort of, apart from the medication um, you sort of just sit in a big loop obviously and there's not really sort of, you can't pick and use the service". (Participant 14)

A small number of participants reported that they have open appointments with professionals, meaning they can request an appointment when they need it. This provided comfort to the participants as they know support is available to them if/when they need it.

"On the whole I get seen pretty quickly as I have an open appointment I just contact them when I need to be seen and I usually get seen within 2 weeks". (Participant 15)

"So weirdly even without seeing him knowing that I've got that instant access is what a) helps me to cope when things go bad but also encourages me to push myself to do things". (Participant 13)

This subordinate theme depicts a mental health service which is reactive rather than proactive, with service users having to become very unwell before they can obtain support. Participants contended that crises could be avoided if support is available to them at an earlier stage of their mental health difficulties. It appears that the service is currently in a vicious cycle whereby participants are supported after they experience a crisis and are then discharged until they experience another crisis. A proactive approach whereby support is available when service users first experience difficulties could prevent service users from getting stuck in this cycle.

6.5.3 Waiting times

Several participants believed the waiting times to access services were too long. Whilst many participants acknowledged the high demand for mental health support, they still believed that the wait to receive support was too lengthy. It was suggested that most people accessing mental health services complain about the waiting times, so this finding may not be specific to the current population being investigated.

> *"That I think that's a general complaint about most people is waiting for the appointment is way too long".* (Participant 20)

> *"I've been waiting about 7 months, it's ridiculous".* (Participant 5)

> *"They say there's a waiting list I think it's because they don't really want to say it's going to be a long wait".* (Participant 20)

> *"Well I mean apart from the sort of waiting times which are always going to be frustrating when services are oversubscribed it's a case of you know it's bin it was all pretty straight forward".* (Participant 19)

> *"I do, I do understand that with counselling the person, person you're seeing does, does have a long wait and it, can be stressed, and can be stressed out quite easily with all the like information they carrying … but it's, it must have been at least a year, at least a year since it was brought up".* (Participant 7)

One participant shared a riddle as a metaphor for his experience of waiting for mental health services. The riddle portrayed a loss of faith in the service, and a sense of exasperation and hopelessness. The participant seems to believe that he may never receive the support he feels he needs.

> *"It's like that riddle, … what's always coming but never arrives? Tomorrow. And that's how I constantly feel in the mental health service. There's always tomorrow, but tomorrow never comes".* (Participant 5)

The impact of long waits on service users was also highlighted. One participant mentioned the detrimental impact to her mental health due to long waits. She stated that she tries to be understanding as she is aware of how in-demand mental health services are but stated that the long waits have negative consequences for her.

Another participant highlighted that whilst people are on waiting lists, their mental health can deteriorate.

> *"I understand all the services are stretched so I try try to be very understanding I know it's not the NHS's fault and it's the Tory bastards but in in terms of the, the effect that that has on me does it work for me, no".* (Participant 11)

> *"Yeah exactly, 'cause like you say when you're waiting six months things can change quite, quite a lot can't they?"* (Participant 10)

Participants conveyed that not knowing their position on the waiting list, and how long they have left to wait, can be anxiety-provoking for them. Participants reported receiving no updates of their progress whilst on the waiting list, which led to frustration. One participant had not heard from the service in so long that she thought she had been discharged; a need for service users to be updated in relation to their position on the waiting list was proposed.

> *"God knows when I'll be seen … I'm not even getting an update … And I, I don't like nagging them and I have via email".* (Participant 11)

> *"I haven't heard anything, I've been, it's like, it's like getting ghosted by your ex or something, it's weird".* (Participant 5)

> *"But there's always things … like waiting lists, they are ridiculous, … there seems to be a lack of organisation sometimes as well… you know like somebody'll go off sick and then I don't hear from them for months and I don't know what's happening, and you know sometimes I've had to go back to my GP 'cause I think I've been discharged and I haven't".* (Participant 10)

This subordinate theme conveyed participants' dissatisfaction with waiting times to access services. Participants believed waiting times are too long and contended there to be negative consequences to service users who are left on waiting lists for significant periods of time. A need for participants to be updated in relation to their progress on waiting lists was evident.

6.5.4 Acute services

This subordinate theme relates to participants' experiences of receiving acute services. Acute services, for the purpose of this theme, relates to the Crisis Team and the mental health inpatient wards. Not all participants had accessed these services, but for those that had, the experience was primarily negative. In relation to the Crisis Team, several participants stated they had found the team unhelpful, indicating they would not reach out to them again when they are struggling.

> "*I've seen crisis teams and I've been forced to A&E but they're not very helpful so I usually refuse them".* (Participant 10)

> *"But I'd rather phone the Samaritans than crisis team these days".* (Participant 1)

> *"The only thing I didn't like was I was just told to take my medication when I called Crisis when I was feeling very suicidal. Because of this experience I am afraid to call them again as I feel like I am bothering them".* (Participant 9)

Several participants recalled experiences where they felt dismissed by the Crisis Team. One participant discussed a time when she called the Crisis Team and the professional indicated that she had spoken for long enough and this resulted in her feeling like she could not continue talking about her difficulties. Another participant recalled a variety of negative experiences with the Crisis Team. She discussed times when she had called the team and they had just advised her to take her medication (without any other support), and other times where a friend had called on her behalf (as she was in crisis) and the team had put the phone down on her friend. These experiences resulted in the participant feeling like a nuisance. The below experiences suggest a need for professionals to listen to the person and show compassion.

> *"I mean the last, one of the last times I phoned up, um in the evening, and basically the guy said oh I've been on the phone to you 45 minutes, and then that made me feel like I couldn't carry on talking".* (Participant 1)

> *"There were a few times when I called the crisis team, um, because I was feeling very low, I was feeling quite suicidal, um, but I, I just got the sense that I was bothering them. Um, and they only really told me to take my medication, and there*

were a few incidences where they actually hung up on me and my friend when he was calling on my behalf 'cause I was in such a mess". (Participant 9)

One participant discussed experiences where she felt she could have been better supported. The one experience was where she attended the Crisis Team, was given a low dose of medication and told she needed to go see her GP in a week. She indicated a need for better support for patients to access the signposted support (i.e. the GP). In the state she was in, she stated she would have been unable to book that GP appointment herself leaving her with no support; she relied on a work colleague doing this for her. She also highlighted that the Crisis Team had referred her for group therapy after her visit (even though the Crisis Team did not know her difficulties) which she felt was inappropriate. A need for the Crisis Team to support service users to book appointments to signposted services was highlighted, as well as a need for support to be person-centred rather than one size fits all.

"I think that initial follow-up is, that could have been crucial. That could have been the difference between, in somebody else's case, I could well imagine that from that visit to Crisis, to the nothing, it could have tipped somebody over the edge". (Participant 4)

"The result of Crisis was shocking, because it was like, you're on a waiting list, okay, but they sent me a letter then for group therapy. They had, they had no clue why I was there. But they were offering me group therapy". (Participant 4)

Another participant recalled numerous encounters that she had had with the Crisis Team. A common theme of feeling dismissed ran through all of her experiences. The participant recalled harming herself after speaking with the Crisis Team on the phone, she recalled wetting herself in her car after being refused support to get home after seeing the Crisis Team, and she recalled her son calling the Crisis Team asking them to check on her (she was in her car in the hospital car park), they refused which later contributed to her taking an overdose. Crisis Teams are there to support people in crisis, but this participant recalls the Crisis Team failing to help her in times of need.

"I can remember coming to see the crisis team once and them trying to send me home and I sat in the car after it and I couldn't drive because I just I knew I was disassociating, I, goodness knows … I tried ringing them to tell them that I was

struggling to leave and again they were dismissing me, um, and it was so bad, I sat in the car and I wet myself because I couldn't even get out to go to the toilets". (Participant 13)

"I'd already been very unwell which was why she'd taken me to meet the crisis team to try and resolve it because when I was ringing them that was ending up worse and I was ending up doing things after speaking to them". (Participant 13)

"They then discharged me, so I, I sat in the car and slept in the car, nobody checked where I was gonna be, whether I was safe, I slept in the car … and it was only because my son messaged me to ask if it would be okay if he … did something and I thought I was answering him fine texting back, but it turns out my text wasn't very legible apparently so he rang me … and he could tell that I wasn't right, so he got out of me where I was, and I was in the little car park by the mental health unit so he asked the crisis team to go and check on me, they refused, so he was so panicked he rang an ambulance. He rang me to tell me he'd rung an ambulance and I panicked 'cause as far as I was concerned there was nothing wrong with me, and because I didn't want to be in trouble for having an ambulance, now looking back it's … just like when there was nothing wrong with me, I scrabbled round in the car found some levothyroxine and took a load of them". (Participant 13)

The above discussion and quotations suggest that the Crisis Team are currently not meeting the needs of this population. Several participants stated that they would not turn to the Crisis Team in their times of need (due to previous experiences), with some participants also recalling very upsetting experiences that they have had with the Crisis Team. Several participants were disappointed with the care they had received from this team; a sense that professionals within this team did not care was evident. A need for professionals in the Crisis Team to listen and be patient and compassionate to service users and their experiences was highlighted.

Also in relation to acute services, two participants had experiences of being inpatients on mental health wards; their inpatient experiences were primarily negative. The one participant stated that she had nightmares about the ward, whilst the other portrayed

a resistance to admission (she referred to the ward as being worse than suffering alone).

> *"And then the last time I went in which I said only for just over the day, and I thought I can't cope with this, this is worse than being out and suffering".* (Participant 1)

> *"I have nightmares about the ward".* (Participant 12)

> *"Although if the option sometimes comes up as hospital, I mean I dig my feet in then, wild, wild horses wouldn't drag me out if I did help it, ya know".* (Participant 1)

Participant 1 discussed the dilemma she encounters when she becomes unwell. She stated that professionals give her the option of either admitting herself on to the ward, or they will section her. Due to her dislike of the ward, she chooses to admit herself willingly so that she can discharge herself whenever she likes. It therefore appears that she admits herself to placate the professionals knowing she has no intention of staying for any significant period of time. When on the ward, the participant believes that professionals do not spend enough time with the patients. The participant recalls the professionals spending most of their time in the office, whilst there are patients out on the ward who could benefit from talking to them. The participant was frustrated that the professionals never seem to be available and believed that the staff were not interested in the patients.

> *"In the last few years I mean sometimes I've thrown my toys out the pram, 'cause *(PROFESSIONAL)* has said aw ya know, I think you need to go to hospital for treatment, and I mean deep down I knew it, but I didn't wanna accept it and as I said the toys go out of the pram, and then I end up going in there…..I'm kinda told well either you go in there of your own volition or we'll section you. So now I know, ya know I've known for years what sectioning means, I think aw no, I'm not gonna stick in that place for 28 days, let's go in of my own volition, and kick myself out. *laughing*"* (Participant 1)

> *"They assess you through a pane of glass. I mean, even if the NA's were coming in, or staff nurses, they would talk to themselves rather than the patients. The way*

I look at it is maybe not everybody they speak to will want to talk back, but at least you tried and you are giving them the opportunity. 'Cause I've seen people really upset in there and the nursing staff are nowhere to be seen and they're not interested". (Participant 1)

*"Cause like in *HOSPITAL WARD* … there's 2 computers, and you know sometimes have 8 in the room. And you're thinking, 2 computers, 8 people, and I know some of you are students so you need to have an idea of what's going on, but surely the rest of you should be on the floor? Or they're on levels, that's another thing as well, if they have got staff, they're on levels. So there's still nobody to talk to".* (Participant 1)

Participant 12 also recalled her experiences of the ward, where she has relatively frequent stays. The participant recalled professionals on the ward speaking to her as if she were a child and snapping at her. Additionally, she recalled a time where a male professional was in her bedroom on the ward which caused her anxiety (due to previous trauma). A need for better communication and sensitivity to service users was implied.

"It's also the way people talk to me as well like I said don't talk to me like I'm three and don't snap at me … 'cause other people a being mean to you … because … when I go onto a ward I treat everyone at first with kindness … and then if they don't treat me back with kindness I will treat them with scepticism, right, I tend to treat everyone well until they hurt me". (Participant 12)

"And then this random guy comes up to me takes half my things only for it to turn out that he didn't need to … And let me tell you I did not appreciate there being a man I didn't know in my room". (Participant 12)

The way in which Participant 12 discussed her inpatient experiences suggested that she often felt unsafe on the wards. She specifically recalled times where there had been physical violence on the wards which made her fearful, resulting in her barricading herself in her bedroom on one occasion. Participant 12 also recalled difficulties she had experienced on the ward in relation to her physical abilities (she is legally blind). The participant believed that she was not adequately supported on the ward for her physical disabilities; professionals seemed to assume that because she

has been an inpatient on many occasions that she can navigate her way around alone. However, the participant indicated that she needs support with this (which she does not get); it seems as if her physical disabilities are overlooked. A need for participants to be supported holistically (physical and mental difficulties) is highlighted.

> *"Well no, not when there are men grabbing crystals from my neck and going you don't need that it's pagan and trying to strangle you with them … And then the guy punched my roommate and then everyone wondered why the heck I barricaded myself in the room".* (Participant 12)

> *"Well I get really confused when I'm on the wards because … they think I know my way around because I've been there so many times, but they have to bear in mind there are like months in between my stays and the only reason I know my way around my grandparents' house so well is that I've been living there my entire life, they're just like oh she's been there a few times she knows everything about this place now, no … yeah, but they're just like they treat me like a person with like full vision".* (Participant 12)

Although the majority of the inpatient experiences shared during the interviews were negative, both participants were able to recall a positive encounter on the ward which had resulted in them feeling supported and valued. One participant recalled a student nurse who had helped her when she felt overwhelmed and another discussed a professional who had supported her interests whilst on the ward. Encounters where professionals had shown compassion were valued and appreciated by service users.

> *"Before I knew I was autistic I remember one time that I'd been sectioned, which didn't exactly enamour me to the hospital in any case, and I said ya know, I was just building up and this one girl, she was a student nurse but she was banking as an NA and she came in and she was brilliant".* (Participant 1)

> *"They usually are very strict about sleep but he was awesome he always made sure my laptop was charged for the nights that I could write and he was like always asking about my novel always talking to me uh talks to me about games of thrones he was just so sweet and he never raised his voice to me neither".* (Participant 12)

This subordinate theme conveyed that participants' experiences of utilising both the Crisis Team and inpatient wards were predominantly negative. In relation to the Crisis Team, several participants felt they were unable to reach out to the team for support as previous encounters with the team had been negative and resulted in them feeling dismissed/unsupported. Areas for improvement on the wards were also highlighted: a need for staff to be available on the ward, a need for professionals to communicate respectfully with service users and for physical health difficulties to be supported as well as mental health challenges.

6.5.5 Unclear pathways

Participants contended that there is no clear pathway to assist service users with accessing services; they described the structure of the service as vague and complex. A desire for a clear pathway for service users was prevalent.

> *"I think, the whole structure of the service is vague, and that's something I did put down".* (Participant 4)

> *"It's incredibly complex. Um, just to see somebody. You don't know who the hell anybody is, you don't know what practice you're meant to go to".* (Participant 5)

> *"But there's … no clear pathway to well, you know, we'll signpost you to the right place".* (Participant 6)

> *"Yeah. I mean I'm grateful for this service anyway, but it just, it would have been nice to have some sort of, path or, ya know".* (Participant 9)

As a result of there not being a clear pathway, participants recalled ending up going around in circles, not knowing who to go to for help and even staff not being aware of who to refer the service users on to. This results in frustration and exasperation for service users, with it feeling like a losing battle to get support. One participant stated that most of the time he had to find the available support for himself rather than him being signposted to it.

> *"Trying to find the right person to talk, to talk to when you know you need help, you go around in circles asking for help, and no one seems to know where I'm supposed to go".* (Participant 7)

"Most of them don't even know where to refer you either so it's like, it's the pharmacist that referred me so it, it, it's lots of gaps, lots of mis, misunderstanding". (Participant 2)

"*There was some beneficial things about it but most of the time I had to go out on my own and find it myself".* (Participant 16)

One participant specifically highlighted a need for a clear pathway for people who suspect they have autism (seeking diagnosis). He recalled his experience and the frustration he felt due to being bounced around professionals until he found someone who would help him/knew about autism. He believes there should be a set process for people seeking an autism diagnosis so that service users know where to start their journey.

"When you think you're autistic, you go to your GP, that seems to be the logical place and there's … no- one else that you can really go to, so you go there, and they don't know, they can't diagnose you, so then you've gotta be signposted back and forth until somebody goes oh yeah I know who you need to talk to … and it seems to be a handful of people who actually deal with it, there's very few people, but … you know those that are, are very highly trained and they can deal with it, it's the rest of the world that can't". (Participant 6)

"If there was some, um I don't know, some regulation that said somebody walks through the door who claims to be autistic then these are the procedures, and this is how we deal with that, um then I think that would be a … distinct improvement over walking in and having to explain your condition … To someone who can't necessarily point you in the right direction". (Participant 6)

Several participants disclosed they were unaware of who they needed to contact if they needed support due to their mental health declining (before crisis point). A need for there to be a designated point of contact was proposed by several participants. It was suggested that reaching out to a designated point of contact could prevent individuals from reaching crisis point.

"Like if I did need support I don't know where to start". (Participant 20)

"Well when I get really, really depressed with the bipolar, I can't function and I get scared and I get suicidal and things like that, so I'd like somebody on the end of a phone". (Participant 15)

"Consistency is kind of important to us, we do need to have that kind of regular this is what you do so if you have a problem you know who to talk to". (Participant 6)

"I just have to contact someone before I do something stupid because if I do something stupid then I end up on the ward". (Participant 12)

"There should be a point of contact, and even if there was a mental health nurse inside your GPs ward, I mean inside your GPs surgery, and you could make an appointment with them separately". (Participant 2)

This subordinate theme suggests a need for clearer pathways, for those seeking an autism diagnosis and for those who already have a diagnosis but need additional support. Participants propose the current pathway is unclear which results in participants going around in circles when trying to access support. Participants indicated the importance of having an available, designated contact to reach out to in times of need to help prevent mental health crises.

6.5.6 Falling through the cracks

A subordinate theme which was revealed through listening to participants experiences of attempting to access support was 'falling through the cracks'. This subordinate theme contains examples of participants' experiences which convey that either they have been bounced around numerous services with no-one taking responsibility for their care, or that their care has been affected by the fact they have co-existing diagnoses. The below participant discussed how she is frequently bounced between her GP and mental health services, with neither stepping up to support her.

"If I go to the GP they're like the mental health services will help you, and then the mental health services say you got your GP, so I'm like okay, I'll be this bouncing ball in the middle". (Participant 2)

Two participants recalled experiences where due to having autism as well as a mental health condition, they had missed out on available support. This could suggest that

people with autism may be disadvantaged when it comes to mental health support provision. This idea is supported by Camm-Crosbie et al. (2018) who found some of their participants fell through the gap in available support due to their co-existing autism and mental health issues. One participant was informed he could not receive certain services due to his dual-diagnosis, whilst another participant was not allowed to attend an OCD group due to professionals not agreeing as to whether or not his issues were due to ASD or his OCD. This difference of opinion resulted in him receiving no support.

> *"They said they can't offer me certain things because I have autism, they, 'cause 'cause I don't have a dual diagnosis or whatever the hell they were saying they said I can't have uh most of the services they offer I can't access because I've got autism and it's beyond their control".* (Participant 17)

> *"*PROFESSIONAL* was trying to … put me into a OCD group 'cause my extreme OCD obviously, he clearly related my autism, … but the OCD group then which was through the ARC turned me down twice because they felt it was more sort of the ASD, not sort of typical … OCD, … but then obviously no-one was giving you clear guidance so obviously … he was saying it's more sort of obviously related to normal OCD, they were saying it's ASD, for my ASD condition obviously superimposed on that and obviously that was causing the issues, and again there was no clarity in the two, so in the end they just said no, no help".* (Participant 14)

Also in relation to dual-diagnoses, another participant was informed they would not offer her mental health support until she had dealt with her drinking problem. This caused the service user to become frustrated as she believed that professionals had not grasped the interconnectedness of her mental health difficulties and her alcohol consumption.

> *"Another thing I've been told is well we're not going to deal with your mental health issues until you go through DASPA and sort out your drinking because but like then that is so backwards that is completely misunderstanding how this is this thing is working the two are completely intertwined".* (Participant 11)

It was suggested by one participant that services find it difficult to deal with people with autism as they don't know what category to place this population in. For example, autism is not a mental health condition, it is not a physical health condition, it is not a

learning disability and therefore, as a result, service users with autism can frequently be bounced around a variety of services. A need for a service to take responsibility for individuals with autism and co-existing mental health conditions was suggested.

> *"Dealing with us in the first place is difficult for the mental health board because they don't know how to categorise us on one hand we're mental health but do we have a mental illness no it's not really an illness that's just how we are we're born that way so you know it's not a mental illness is it a learning disability well clearly not some of us can learn it depends on whether we're being taught so it's not really a learning disability it's how do you classify it. It's not medical so we get passed off it's not mental health because we can't, we don't have any facilities for that so we'll pass you off to medical but medical's looking at it, there's nothing physically wrong with you know you're fine so we can't treat you with medications we can't help you in in any way that we understand so they bring us back to the mental health service because it's … not their responsibility, we just kinda get passed back and forth until somebody sits up and goes yes actually I do know what this is and maybe we can help". (*Participant 6)

This subordinate theme evidenced that some service users are falling through the cracks. Participants believed that service users with autism sometimes get passed back and fore between services with no service taking responsibility and offering support to them. A need for services to better support people with co-existing conditions was also evident, with some participants being declined support due to having dual-diagnoses. This suggests a need for services to support people holistically rather than categorically.

6.5.7 Transition to adult services

At approximately the age of eighteen years, service users should transfer from the Child and Adolescent Mental Health Service (CAMHS) to Adult Mental Health Services (AMHS). Not all of the participants in this study had accessed CAMHS, many had only started accessing support as an adult. For those who had transferred from CAMHS to AMHS, there were significant inconsistencies in the process (referred to as the transition). The below participant was told that she would transition from CAMHS (which she had been accessing for approximately seven years) to AMHS, but had in

fact not been transferred; she had unknowingly been discharged from services altogether and had to refer back in.

> *"When I turned 18, I was discharged from CAMHS and felt like I was forgotten about. I wasn't contacted at all and I had to be referred again".* (Participant 9)

> *"I left an appointment with CAMHS, and they said, I can't really remember, but, they said oh we'll be in touch or whatever, and then I had nothing. No phone call, no letter.* (Participant 9)

> *"That was when they told us oh … the first thing you should have done was go to your GP, but I didn't know that, no one told me to do that".* (Participant 9)

Another participant was transferred to AMHS but was not provided with a support plan as promised; he now only gets medication reviews from the service. The participant felt very let down by the service; this frustration has resulted in him not wanting to utilise the service at all. This participant argued that the service needs to understand that autism is a life-long condition, indicating a need for ongoing support past the age of eighteen years.

> *"After I finished with CAMHS … they were supposed to put a support plan, and that never really happened, they just took control of my meds and it just turned into a med review". (Participant 17)*

> *"Well I don't, I don't want anything off them now to be honest".* (Participant 17)

> *"They need to make sure they stop slipping under the net … they need to take the mental health of people with autism a lot more seriously because it doesn't get easier when you're an adult, it isn't something you grow out of, it as I said earlier, … it's very important that people from the age of eighteen like I said … I was very lost, and … there's people, I can see people in the same situation now, and I see eighteen year olds in the group talking about their experience, that go through the same things as I had to go through when I was eighteen, and I don't think it's fair".* (Participant 17)

For other participants, they discussed a very smooth transition from CAMHS to AMHS. One participant hardly noticed the transition from CAMHS, with another participant

discussing how she had a supported transition to AMHS where she was introduced over time to the new professionals she would be supported by.

> *"I just went straight over not thinking anything".* (Participant 20)

> *"Yeah, and so she was learning all about me from my social worker at the time … and working alongside her, and so I got to know *PROFESSIONAL* really well and by the time I was eighteen I was all set to go to the adult services cause I'd already fallen in love with *PROFESSIONAL* platonically".* (Participant 12)

This theme evidences the inconsistencies in the transition process for service users. One participant was discharged at eighteen with no support (needing to re-refer herself), another was not given the support he was promised, whilst others had a seamless, supported transition. There needs to be a more consistent, equitable process for transitioning service users from CAMHS to AMHS.

6.5.8 Broken promises

Several participants discussed times where they had been made promises by professionals which never come to fruition. The result of broken promises is a disappointment with professionals and the service as a whole and this impacts upon the service users' satisfaction with mental health services. One participant even referred to mental health professionals having a reputation of never fulfilling promises.

> *"Mental health professionals always are … at the foot of promises that never get fulfilled".* (Participant 8)

Participants shared their difficulty in dealing with people breaking promises. Participants stated that they hold people to their word, including professionals, and when people break their word, this leads to disappointment and frustration.

> *"If you say something to me, I will hold you to that, even if you've forgotten, and that's something I find really difficult to deal with in society".* (Participant 2)

> *"I like to have answers … I like you know, I don't like to be just told this is what you need to get when I was promised something, I'm very stubborn … in that way ... it's frustrating because you don't get what you what you deserve".* (Participant 17)

Several participants referred to being let down on numerous occasions, where they had been offered support (predominantly counselling) and then never received it. Additionally, one participant was told he had been referred for counselling but then received an invite to a mindfulness course. This left him feeling misled and discouraged.

> *"No I was offered counselling once or twice, especially when, um, my depression started … But I just never had it … I wanted it and they didn't give it".* (Participant 20)

> *"When I was told I was being referred for this service uh I think it sort of accidentally got my hopes up a tiny bit 'cause I think the word they used was counselling, so I felt like ah great, … and then when I got the letter that it was a mindfulness course initially I was a bit like ahhhh great. I was a bit deflated 'cause I thought I'm just kind of going through the motions rather than getting done what I needed to get done".* (Participant 18)

Another participant recalled her experience of trying to obtain counselling. She was told she could have counselling and when she met with a professional who she believed would be able to offer counselling, the professional was unaware of why she was referred. The participant also met with another professional in her home who told her that she would do counselling with her and then the participant never saw that professional again. The participant portrays a sense of having been continuously let down, resulting in her feeling like a nuisance.

> *"Like my psychiatrist said I generally talk to the group and I've talked to the other people and they recommend that you go and have counselling, I hold onto that, and when that woman sort of going in all bright eyed and starry eyed and then the woman sits there looking at me like well 'what's your problem'? It just comes crushing down and it's like, it's that constant um, feeling of a nuisance".* (Participant 2)

> *"So anyway I had an appointment at the doctors with the mental health lady that was supposed to put me on counselling. She said to me, what you here for, and I thought as soon as I hear that I know that this lady is gonna be, trouble. So anyway, she turned around and she says to me, I have no idea why you are here,*

I don't think that we can offer you this this and this and this, and our stomach just sank and I thought here we go again". (Participant 2)

"I've asked for counselling and the, the community nurse came and she said yes we'll give you counselling, it'll even be me she said, and I said oh you're really lovely I'd love that, and then no more from her". (Participant 2)

This subordinate theme, broken promises, discussed examples of how participants had been let down by services. Participants shared how they found it difficult to deal with professionals not keeping their word and how broken promises can result in service users feeling misled, unimportant and frustrated.

6.5.9 Gratitude

Although the majority of participants recalled some or many negative experiences of accessing mental health services, many participants showed gratitude towards the service. Many participants did not want to come across as ungrateful during the interviews, with several attributing their life to mental health services. It was suggested by several participants that if they had not received support from mental health services that they would no longer be alive.

"Without it I probably would you know, I'd, I would be dead … I might have even goodness knows, I might have even ended up hurting other people, goodness knows". (Participant 13)

"Oh well without it I wouldn't be here … and if I was here, then I probably would be institutionalised by now". (Participant 11)

"I would probably be dead by now if I hadn't had access. Therefore it has given me a life I would have never had". (Participant 15)

"*I think it actually helped because if I hadn't accessed the services, I probably wouldn't be here today".* (Participant 1)

As well as being grateful for the support the service has provided, several participants specifically praised certain professionals that had supported them along the way. However, one participant disclosed that she was scared of losing her current support as she finds it "crushing" when professionals discharge her.

"I honestly believe that without her frequent and decisive interventions during some intensely difficult times, I would not be here today". (Participant 6)

*"I think that people like you, people like *PROFESSIONAL*, people like that wonderful psychiatrist I've had have impacted really well on my life, and I, I really appreciate that, really positive, it's just when they go it becomes crushing, that's what crushes me". (Participant 2)*

This theme illustrates that participants are grateful for the support they have received from mental health services, as well as the professionals within it. Several participants attributed their life to the service, with some believing that the service prevented them from being institutionalised or potentially harming others. This theme conveyed the importance of mental health services and the role they play in keeping service users safe.

6.6 Theme 5: Making Accommodations

Accommodations, for the purpose of this thesis, can be considered adjustments that can be made to better support service users' needs. This superordinate theme comprises of four subordinate themes: (1) Environments, (2) A need for consistency, (3) Support preferences, and (4) Advocacy. These subordinate themes convey areas in which mental health services could make accommodations to better support the current population. A need for environments to be accessible to service users, a need for services to be consistent for service users, a need for participants' support preferences to be considered and a need for mental health services to act as an advocate for service users when required arose from the analysis.

6.6.1 Environments

A need for services and professionals to be aware and considerate of service users' sensory sensitivities was highlighted. Participants provided examples of where the environment had impacted upon their experience of mental health services. Several participants stated that they had sensory sensitivities and the below quotations evidence some of the areas that participants have found troublesome, such as lighting, acoustics, temperature and clocks (clocks not working and the sound of clocks ticking). One participant recalled his experience of a consultation room which he found was not

appropriate for his needs; the layout and condition of the room were specifically noted as areas for improvement.

"Mental health doctor doesn't ask you about obviously the lighting the temperature you know, even the acoustics of the room can obviously [cause] issues … you get none of that sort of asked before … so you, you feel automatically uncomfortable before you get there". (Participant 14)

"Bright lights make it a bit difficult. … Especially if there's any chance you're gonna be lying down staring up at them". (Participant 8)

"The option for lights or no ticking clocks you know that kind of stuff". (Participant 10)

"It's awful, things like, if you're going in and you're sitting there, and the clock's not working. And I don't know how many places, rooms in here, but the clock does not work". (Participant 4)

"It's always in the same block and it's always the same office whichever doctor you see, it has no windows, it's quite an odd shape room and you know obviously my OCD kicks in, its bits of like paper and stuff on the floor and you pull off paper you get bits of paper, um and its always the same room, the room itself isn't very geared for my needs … Um obviously I need some sort of natural light maybe a window um to see … obviously … the doors there … desk is obviously here, then it's obviously a very enclosed wall space and you have to sit with your back to the door and I like to see out a window or a door and when I when I sit in this office you can't see that". (Participant 14)

Several participants specifically discussed the waiting room area and highlighted elements of the waiting room they disliked. The amount of posters on the walls, TVs playing in waiting rooms, lighting and specifically the layout of waiting rooms were mentioned. Small changes made to the environment could help to alleviate anxiety for some service users; one participant mentioned that a sign was put up offering service users the option of having the TV turned off in the waiting room which showed consideration.

"There's posters everywhere". (Participant 8)

"There were things like the TV was always on in the waiting room". (Participant 8)

"They got a sign put up at reception that said if it's bothering you, ask, cause then we'll turn it off". (Participant 8)

"Dimming the lights, ... slant the blinds, ... yeah. It's the fact that every waiting room, they're designed in, in a way that, you can't get away from people". (Participant 4)

"And they make you sit round in a circle and stare at each other….like everyone, everyone is trying not to stare at each other". (Participant 8)

"And then, it's, I tend to sit then, when I'm here, I sit with my back to anybody coming in 'cause I don't want to, to see people coming in". (Participant 4)

"So if you walk in and someone's already there, you can sit with your back to them". (Participant 8)

A desire to have the option of a quieter waiting space for service users was shared by one participant. Having a quieter waiting place would allow service users with sensory sensitivities to avoid loud noises/overwhelming environments which would help to alleviate any related discomfort.

"Maybe even if it is practical like have a, a quieter waiting space you know, I wish hospitals would do that as well you know, have like a, a sort of side quieter … area like … You know where there's no screaming kids or people talking and … you get the picture". (Participant 10)

This subordinate theme highlighted that many individuals with autism might experience sensory sensitivities; these sensitivities can impact on service users' experiences with healthcare. Participants shared examples of things that have caused them discomfort when accessing mental health services such as the lighting, noise levels and temperature. Making small changes, such as minimising the number of posters on walls in waiting rooms and not having ticking clocks, could potentially improve the healthcare experience for service users.

6.6.2 A need for consistency

The importance of consistency was referred to by many participants, mainly in relation to professionals, but a need for consistent, regular appointments was also mentioned. Many participants expressed a desire to have a consistent professional rather than seeing lots of different professionals; it was contended that having a consistent professional makes it easier for service users to develop rapport. Participants also believed that having a regular professional assisted with continuity of care. One participant specifically mentioned her experience of the Home Treatment Team, where she never knew what professionals would arrive and this led to anxiety.

> *"With the home treatment you never know who's gonna show up, and how many … and you never know when your appointments were gonna be, it was kind of I'll call you tomorrow or the next day and we'll arrange an appointment and you never know when to expect the phone call, who was gonna turn up".* (Participant 3)

> *"Yeah and if the workers were more consistent as well, 'cause I feel like I've seen you know so many different workers you know, which … that doesn't exactly help".* (Participant 10)

> *"Yeah I mean its like people wouldn't go up to a complete stranger would they and just start talking about all their personal stuff would they? … Nobody would, so that, that would be helpful if we had consistency with the workers instead of just getting passed around".* (Participant 10)

> *"Some staff now they've got to know me, so staff that I'm with long enough for them to get to know me, that actually trust what I say … Those are the ones I get on [with] best and that's why I think continuity of care is so, so important because ... they get to know you as a person rather than assessing you according to everybody else, but that's a two way street as well because it takes you being willing to correct them".* (Participant 13)

> *"At the beginning of my treatment I saw way too many different doctors that I couldn't figure out how they could treat me if there was no continuity. Therefore I didn't feel in safe hands and clammed up".* (Participant 15)

Additionally, some participants found their appointments to be irregular and infrequent. One participant expressed a desire to know how many appointments she would be

having in advance so that she could feel informed. Another participant recalled having appointments with months in-between and conveyed a preference for having contact more routinely. A need for participants to know upcoming appointments in advance and for them to be regular was suggested.

"I put down the, the infrequency or the random appointments". (Participant 4)

"It was blocks of perhaps 4 weeks, and then, you'd get to end of the 4 weeks and you didn't know whether you were having another, I don't know". (Participant 4)

"Where I've had like you know an assessment and then waited six months, have to go in for another assessment, and then another six months, at least that was done over in like two weeks". (Participant 10)

This theme expressed a desire for a more consistent approach to participants' care, including their professionals and their appointments. Participants contended that having a regular professional allowed them to better develop rapport and could assist with the continuity of their care. A need for regular appointments was suggested, rather than having appointments which are very spaced out and unpredictable.

6.6.3 Support preferences

This subordinate theme imparts participants' preferred methods of support. Many participants indicated a preference for one-to-one support from professionals rather than intervention being delivered in group settings. Several participants stated that attending group intervention made their difficulties worse rather than better. A dislike for role-play in group-delivered support was also highlighted. There seemed to be consensus that people with autism "don't do" groups.

"Like I said more one to one stuff as well … 'cause autistic people don't do groups very well". (Participant 10)

"The fact that if you need extra help it's all about group therapy, I hate groups immensely, they make my problems worse rather than better, therefore I get very frustrated and find myself more isolated". (Participant 15)

"They seem to have this, um, a thing where they think groups seem to work. This group thing is awful, because if you've ever been in a group in a room, like say

like this, with a group of people that are truly down, I'm not being horrible, but I went to those groups, didn't we? And we sat there with those people I come out of there feeling far worse than when I went in, and I argue there's mountains out there, there's a sea down the road why are, why are we all sitting here feeling sorry for ourselves when there's so much wonder out there and that just makes me really sad". (Participant 2)

"The problem is with groups I often have to take somebody with me cause when I get overwhelmed I can't really explain it very well and I just kind of end up running off … and the thing is then though, I can't be as open if I've got somebody with me 'cause there's certain things I can't talk about so … what I'm finding is the emphasis seems to be on groups and there's not so much one to one stuff available". (Participant 10)

"From there then I was like so what supports available and I was told well, there are social groups which I kind of laughed a little bit at 'cause I was like you know … that's not really what autistic people love too much". (Participant 11)

"It was everything ya know, it was like the whole role play thing, and nobody likes role play, nobody likes role play". (Participant 3)

Whilst many participants conveyed a dislike for intervention being delivered in a group setting, several participants discussed the benefit of attending an autism social group. The social group was considered a good place to confer with people who have the same difficulties, to gather advice on any issues experienced, and to obtain information about autism. One participant expressed a desire for there to be more autism social groups in his area and suggested that attending an autism social group could potentially reduce his need to visit the GP.

"Cause at the time I was trying to find out as much information as I possibly could and of course the easiest way to do that is to you know confer with people who have the same issues". (Participant 19)

"It's mainly, it's mostly like … instead of feeling isolated then your alone against the world you can try and find like-minded individuals who are going through the same and might offer some advice". (Participant 16)

"The group at first because again you know, it wasn't something I'd really thought about before and suddenly I was on the spectrum, so I'm learning all of this about it and being around people who are also on the spectrum taught me a lot about how we are, and who we are, … and also I, … the unusual thing is that the group was, it was a social group and it worked as a social group, you know people got along just fine which contradicted what I'd read about, what I'd researched, ... that contradicted all that information, um... and everybody in the group seemed to do … well". (Participant 6)

"Maybe, obviously some more support groups potentially in the area … again then obviously that would … the knock on effect then wouldn't have to see the GP or, or the doctor so often because I can access support there 'cause most of those groups would obviously have to have professionals there … which then obviously they could sort of refer in then". (Participant 14)

Also in relation to support preferences, some participants discussed a need for there to be alternatives to solely utilising verbal communication; these participants displayed a desire to communicate through writing. One participant discussed interacting with her professional via writing and how positive that experience had been for her. Another participant expressed a desire for any instructions given to her to be written down as she finds it difficult to digest the information. Another suggestion was the ability for service users to be able to communicate with professionals via email prior to their first appointment; service users could describe their difficulties and experiences via written means which could alleviate their anxiety during the first appointment.

"The other thing is, I write to him, he allows me to interact through writing … and that has been fantastic. Um, because I'd come out of a session, and then I, I just gotta try and make sense of it, and unpick it, and, and sometimes that day I'll write copious notes. Or it might take a few, but he's happy, and I would send them to him, and he'd always read everything before the next session". (Participant 4)

"Maybe the ability to like contact … like mental health people with like via email or something like before the sessions so then they can get like a chance perhaps to read through it and know what questions to ask rather than us having to like babble on and get nervous and freeze up and …start talking about other things". (Participant 10)

"Simply giving me information like sitting there and saying you gotta do this this and this and this and I'm trying to grasp it, why don't they write it down, and say oh here's a leaflet to follow, this is what you follow, you phone this number and that, they don't even do you that, they talk to you as if, what I'm trying to say is, it's as if one, everything fits everybody, one size fits all, you tell me something I'm supposed to grasp it as if an ordinary person's supposed to grasp it, so it's like they're saying yes autism exists, and mental health, but in reality it doesn't, it only exists as a label, it doesn't exist as a reality, do you see what I'm saying?" (Participant 2)

This subordinate theme captured a variety of support preferences held by service users. The majority of participants indicated a strong preference for one-to-one support with professionals and a dislike of groups. However, the value of attending an autism social group was acknowledged. Additionally, the ability for service users to be able to communicate with their professionals via written means as well as verbal means was highlighted.

6.6.4 Advocacy

Relevant to the current project, advocacy aims to ensure that service users' voices are heard and that their views are respected in relation to decisions relevant to their healthcare. Participants recalled times where mental health professionals had been required to be their advocates; some participants shared experiences where a professional had supported them and acted in their best interests to ensure their needs were considered.

"But I myself need an advocate, I need somebody who can speak on my behalf, you know that's something we all need". (Participant 6)

"She knew about autism, she spoke to me, gave me my own voice, understood my needs". (Participant 7)

Participants found having a mental health professional as an advocate to be a positive experience; where service users had felt they were being dismissed, the advocate ensured that the service users' wishes had been heard, which resulted in positive outcomes for the service users. One participant was on a physical health ward as she was very unwell with sepsis and a mental health professional visited the ward to help

her communicate her needs to the ward staff; this resulted in an improved experience of the ward for the service user. It's important to remember that physical health and mental health are not independent, as acknowledged by WHO (2018) in their definition of health, and this needs to be considered when providing support to service users.

> *"The *PROFESSIONAL* has influenced in a positive way when she, when she was with me people listened, people listened to my needs, things got sorted but I've been trying to sort them for 3 years. Before that, before that, no one listened".* (Participant 7)

> *"Because having an advocate, and also having somebody who can tell me, like I said … if I sit in a dark room everybody looks at me, like you know she's just odd, but having *PROFESSIONAL* being able to explain to me why I'm doing these things, that, that, that's been a positive".* (Participant 4)

> *"Yes, she helped me write down a list of things that I, my needs, and then she stayed, insisted on staying put until she got to speak to the ward sister. And, I'll tell you, I had tried to talk to them, but they hadn't listened".* (Participant 8)

However, one participant did share an experience whereby she had informed services she wanted to bring a supporter (from an external organisation) to one of her appointments. The supporter was unable to attend the appointment on the date first issued to the participant and as a result the participant was dropped to the bottom of the waiting list; this led to her having to wait almost a year and a half for an appointment with the service.

> *"It must have been a year, year and a half. I mean it was bad in my case because I wanted to go with support, and the first date they gave me the person supporting me couldn't make it … so that bumped me down the bottom of the list".* (Participant 8)

This subordinate theme illustrated that on occasion mental health services may be required to advocate for service users. Participants' experiences of mental health professionals as advocates for service users was very positive. However, one participant discussed an experience whereby wanting an advocate in an appointment with her had significantly delayed her care. There is a need to ensure service users are not disadvantaged for wanting representation present during their appointments.

6.7 Summary

The findings contained within this chapter convey the experiences of adults with autism of accessing mental health services. All participants reflected on their experience of receiving their diagnosis, from the assessment stage through to post-diagnosis. There appeared to be no consistent autism assessment process and a need to improve the way autism diagnoses are shared with service users was evident. For the majority of participants, receiving their autism diagnosis contributed towards better self-understanding and acceptance. The post-diagnostic support offered to participants was mostly either non-existent or inadequate, leaving many participants seeking further information. The negative effect of being diagnosed later in life was also discussed, with several participants believing that if their autism had been diagnosed earlier, they may not have developed mental health difficulties.

In relation to staff awareness of autism, participants highlighted a need for professionals to have some knowledge of what autism is and the impact that it has on individuals. Participants suggested that professionals having or not having autism knowledge impacted on their experience, i.e. participants believed they were more likely to have positive interactions with professionals knowledgeable in autism compared to those who are not knowledgeable. A need for professionals to have an awareness of masking was also proposed due to the fact that masking can hide some of the difficulties that people with autism experience.

An overall requirement to facilitate communication was proposed. A need to ensure successful communication during professional-service user interactions, a need to utilise service users' preferred method of contact (written), a need to communicate in a non-ambiguous way and a need to improve communication between and within departments was proposed. In addition to facilitating communication, the majority of participants highlighted areas of the mental health service that they were dissatisfied with, including: the way medication is issued, the fact that the service is reactive (rather than proactive), long waiting times, acute service provision (the Crisis Team and inpatient wards), unclear pathways to support, people falling through the cracks, the transition from CAMHS to AMHS and broken promises. However, whilst participants acknowledged that all of these areas would benefit from improvement, participants conveyed how grateful they were for the support they had received from the service,

with several participants stating that they would no longer be alive if it were not for the service.

A need to make accommodations was also evident. A need to make environments autism-friendly, a need to offer more consistent support to service users, a need to honour participants' support preferences and a need for mental health professionals to be advocates for service users were highlighted.

This chapter has presented the findings of Phase 1, which explored the needs and experiences of adults with autism and co-existing mental health conditions of accessing mental health services. The following chapter will present the Phase 2 quantitative findings exploring mental health professionals' knowledge of ASD.

Chapter Seven: Results – Phase 2

7.1 Introduction

This chapter will convey the quantitative results from Phase 2 of the current study. Specifically, it will explore the findings of the ASD Knowledge Questionnaire distributed to mental health professionals in adult mental health services. This questionnaire measured ASD knowledge as well as ASD confidence (professionals' confidence in their ASD knowledge). A total of 58 mental health professionals completed the questionnaire. This chapter first provides descriptive statistics before moving on to inferential statistics. The descriptive statistics section include the following: an assessment of the internal consistency of both scales, scale descriptives, descriptives for group comparisons, item descriptives, and finally, tests of normality for both scales. The inferential statistics will discuss each hypothesis in turn and provide the statistical analyses undertaken to investigate each research hypothesis.

7.2 Research Hypotheses

One study aim was to evaluate the ASD knowledge of professionals working within Adult Mental Health Services in the Health Board. For the purposes of statistical analysis, this aim has been broken down into the following research hypotheses:

- Hypothesis 1: Mental health professionals will have good knowledge of ASD.
- Hypothesis 2: There will be a relationship between ASD knowledge and ASD confidence.
- Hypothesis 3: ASD knowledge will vary by occupation group.
- Hypothesis 4: ASD confidence will vary by occupation group.
- Hypothesis 5: ASD knowledge will be higher for those that have received ASD training compared to those who have not.
- Hypothesis 6: ASD confidence will be higher for those that have received ASD training compared to those who have not.

7.3 Variables

For Phase 2, there were three independent variables [occupation group, ASD training undertaken and years of service] and two dependent variables [ASD knowledge

scores and ASD confidence scores]. For occupation group there were three categories [Therapies, Social Care, and Nursing], with two categories for ASD training undertaken [Yes or No]. Years of service was the number of years since the professional qualified/started their role. Preliminary analyses showed years of service had no significant effect on findings and therefore this variable has not been included in this chapter.

7.4 Descriptive Statistics

7.4.1 Internal Consistency

A Cronbach's alpha was undertaken to assess the internal consistency of the two scales individually, the scale measuring ASD knowledge and the scale measuring ASD confidence. A Cronbach's alpha aims to establish whether items within a scale are measuring the same construct, i.e. the test measures the homogeneity of the scale (Gray, 2018).

The ASD knowledge scale consisted of 28 items (presented as statements) and had an excellent level of internal consistency, as determined by a Cronbach's alpha of .92 (please see Appendix 22). The confidence scale, also consisting of 28 items, was similarly found to have an excellent level of internal consistency, as determined by a Cronbach's alpha of .96 (please see Appendix 23).

For both scales, no values in the Corrected Item-Total Correlation column were below .3, and none of the values in the Cronbach's Alpha if Item Deleted column varied dramatically from the Cronbach's alpha for each scale (see Appendix 24 & 25); therefore, no items needed to be removed from either of the scales to improve internal consistency (Field, 2018).

7.4.2 ASD Knowledge and ASD Confidence Scales

Table 18 summarises the descriptive statistics. For the knowledge scale, 0 was the minimum score that could be obtained, with a maximum score of 28 indicating that the respondent got 100% of the answers correct. The lowest score obtained on the knowledge scale was 1 (3.57%) with a highest score of 25 (89.29%). A mean score of 18.03 on the ASD knowledge scale means that the average correct responses was 64.40% (to 2dp).

Table 18: Descriptive statistics for both questionnaire scales

Scale	N	Mean score	Standard Deviation	Minimum Score	Maximum Score	Range
ASD Knowledge	58	18.03	5.82	1	25	24
ASD Confidence	58	51.74	13.02	28	77	49

For the confidence scale, the lowest score that could be obtained was 28 which meant that the participant stated they were 'Not at all Confident' for every statement, with 84 being the highest score that could be obtained, which indicated that the participant answered 'Very Confident' for every statement on the scale. For confidence, the lowest score attained was 28, the highest score obtained being 77, with a mean score of 51.74 (to 2dp). The following section discusses ASD knowledge and confidence scores in relation to the two independent variables in this study [occupation group and ASD training undertaken].

7.4.3 Occupation Group

This section compares ASD knowledge and ASD confidence scores across the three occupation groups (Therapies, Social Care and Nursing). Table 19 contains the mean ASD knowledge scores across the three different occupation groups with Therapies having the highest mean ASD knowledge score (21.27), and Social Care having the lowest mean ASD knowledge score (14.64). The lowest score achieved in Therapies (17) was considerably higher than the minimum scores achieved by the other two occupation groups. Similar maximum scores were seen across the three occupation groups. Notably, the range of scores for Therapies (8) was much lower than for Social Care (24) and Nursing (19).

Table 19: Table exploring the effect of occupation group on ASD knowledge scores

Occupation Group	N	Mean ASD Knowledge Score	Standard Deviation	Minimum Score	Maximum Score	Range
Therapies	22	21.27	2.31	17.00	25.00	8.00
Social Care	11	14.64	9.20	1.00	25.00	24.00
Nursing	25	16.68	4.88	5.00	24.00	19.00
Total	58	18.03	5.82	1.00	25.00	24.00

The effect of occupation group on ASD confidence scores is shown in Table 20 below. In addition to having the highest mean ASD knowledge score, Therapies also had the highest mean ASD confidence score (59.86). In relation to confidence, the mean scores for Social Care and Nursing were very similar (46.82 and 46.76 respectively). Professionals from the Therapies group achieved both the highest minimum score (36) and the highest maximum score (77). The minimum ASD confidence scores for both Social Care and Nursing were very similar (68 and 69 respectively). The range of ASD confidence scores were similar across all three groups.

Table 20: Table exploring the effect of occupation professional group on ASD confidence scores

Occupation Group	N	Mean ASD Confidence Score	Standard Deviation	Minimum Score	Maximum Score	Range
Therapies	22	59.86	12.57	36.00	77.00	41.00
Social Care	11	46.82	13.59	28.00	68.00	40.00
Nursing	25	46.76	9.50	29.00	69.00	40.00
Total	58	51.74	13.02	28.00	77.00	49.00

7.4.4 ASD Training Undertaken

This section explores the effect of ASD training on ASD knowledge and confidence scores. Out of the 58 participants, 24 (41.4%) had received ASD training and 34 (58.6%) had not received ASD training. The mean ASD knowledge score was higher for the group that had received ASD training (20.54) than for the group who had not received ASD training (16.26). The lowest score obtained in the group who had undertaken ASD training was 9, compared to a lowest score of 1 in the group who had not undertaken ASD training. The maximum scores achieved were similar between the groups. The range of scores for the ASD training undertaken group was smaller than that for the ASD training not undertaken group (16 and 23 respectively).

Table 21: Table exploring the effect of ASD training on ASD knowledge scores

ASD Training Undertaken	N	Mean ASD Knowledge Score	Standard Deviation	Minimum Score	Maximum Score	Range
Yes	24	20.54	3.72	9.00	25.00	16.00
No	34	16.26	6.42	1.00	24.00	23.00
Total	58	18.03	5.82	1.00	25.00	24.00

Similar to the trend seen in ASD knowledge scores, the group that had received ASD training had a higher mean ASD confidence score (60.13) than the group that had not had any ASD training (45.82) (see Table 22). The minimum and maximum scores achieved in the group that had undertaken ASD training (39 and 77 respectively) were higher than the corresponding scores for the group who had not undertaken training (28 and 69 respectively). The range of scores for the group who had undertaken ASD training (38) was smaller than for the group that had not undertaken training (41).

Table 22: Table exploring the effect of ASD training on ASD confidence scores

ASD Training Undertaken	N	Mean ASD Confidence Score	Standard Deviation	Minimum Score	Maximum Score	Range
Yes	24	60.13	12.11	39.00	77.00	38.00
No	34	45.82	10.18	28.00	69.00	41.00
Total	58	51.74	13.02	28.00	77.00	49.00

7.4.5 Individual Questionnaire Statements

The individual items that were contained within the questionnaire, and the corresponding responses for both knowledge and confidence are reported below. Table 23 shows participants' responses for the individual items contained within the questionnaire. In relation to ASD knowledge, percentages are provided to indicate how many participants responded correctly, how many responded incorrectly and how many indicated that they really did not know the answer. The correct response for each questionnaire item can be found within the answer sheet in Appendix 18. For each item, participants were asked to indicate how confident they were in answering the statement; this information is also detailed in Table 23 for each item with the response options being: Not at all Confident, Confident or Very Confident. In Table 23, all values reported are to one decimal place. Due to rounding, some percentages may not add up to exactly 100%.

Table 23: Knowledge and confidence responses for individual statements

1. Adults can never be diagnosed with ASD.

Really Don't Know (%)	Wrong (%)	Correct (%)
3.4	3.4	93.1

Not at all Confident (%)	Confident (%)	Very Confident (%)
12.1	41.4	46.6

2. There is currently no medical test to diagnose ASD.

Really Don't Know (%)	Wrong (%)	Correct (%)
24.1	27.6	48.3

Not at all Confident (%)	Confident (%)	Very Confident (%)
46.6	44.8	8.6

3. ASD is more frequently diagnosed in males than in females.

Really Don't Know (%)	Wrong (%)	Correct (%)
31	5.2	63.8

Not at all Confident (%)	Confident (%)	Very Confident (%)
36.2	50	13.8

4. ASD tends to run in families.

Really Don't Know (%)	Wrong (%)	Correct (%)
25.9	17.2	56.9

Not at all Confident (%)	Confident (%)	Very Confident (%)
51.7	39.7	8.6

5. There is no single recognised treatment for ASD.

Really Don't Know (%)	Wrong (%)	Correct (%)
19	13.8	67.2

Not at all Confident (%)	Confident (%)	Very Confident (%)
39.7	41.4	19

6. The biggest problem with diagnosing ASD is that symptoms do not appear until age five or older.

Really Don't Know (%)	Wrong (%)	Correct (%)
27.6	27.6	44.8

Not at all Confident (%)	Confident (%)	Very Confident (%)
53.4	37.9	8.6

7. An individual can be diagnosed with both ASD and Learning Disability.

Really Don't Know (%)	Wrong (%)	Correct (%)
12.1	1.7	86.2

Not at all Confident (%)	Confident (%)	Very Confident (%)
22.4	55.2	22.4

8. ASD is a brain disorder.

Really Don't Know (%)	Wrong (%)	Correct (%)
25.9	24.1	50

Not at all Confident (%)	Confident (%)	Very Confident (%)
53.4	36.2	10.3

9. There is currently no cure for ASD.

Really Don't Know (%)	Wrong (%)	Correct (%)
8.6	0	91.4

Not at all Confident (%)	Confident (%)	Very Confident (%)
17.2	48.3	34.5

10. Most evidence suggests that ASD can be caused by vaccines.

Really Don't Know (%)	Wrong (%)	Correct (%)
15.5	3.4	81

Not at all Confident (%)	Confident (%)	Very Confident (%)
27.6	36.2	36.2

11. Many individuals with ASD have trouble sleeping.

Really Don't Know (%)	Wrong (%)	Correct (%)
44.8	20.7	34.5

Not at all Confident (%)	Confident (%)	Very Confident (%)
55.2	37.9	6.9

12. One common treatment for ASD is Dialectical Behaviour Therapy.

Really Don't Know (%)	Wrong (%)	Correct (%)
43.1	39.7	17.2

Not at all Confident (%)	Confident (%)	Very Confident (%)
56.9	25.9	17.2

13. Individuals with ASD have difficulty interacting socially.

Really Don't Know (%)	Wrong (%)	Correct (%)
5.2	3.4	91.4

Not at all Confident (%)	Confident (%)	Very Confident (%)
13.8	48.3	37.9

14. After being diagnosed, the presentation of ASD remains stable throughout the individual's life.

Really Don't Know (%)	Wrong (%)	Correct (%)
15.5	8.6	75.9

Not at all Confident (%)	Confident (%)	Very Confident (%)
25.9	53.4	20.7

15. Problems during birth (e.g. foetal distress, breech presentation) have been linked to ASD.

Really Don't Know (%)	Wrong (%)	Correct (%)
48.3	13.8	37.9

Not at all Confident (%)	Confident (%)	Very Confident (%)
69	27.6	3.4

16. Many scientists believe that ASD is a product of abnormal brain development.

Really Don't Know (%)	Wrong (%)	Correct (%)
51.7	3.4	44.8

Not at all Confident (%)	Confident (%)	Very Confident (%)
70.7	25.9	3.4

17. A larger proportion of individuals with ASD remain non-verbal throughout their lives, compared to the general population.

Really Don't Know (%)	Wrong (%)	Correct (%)
29.3	25.9	44.8

Not at all Confident (%)	Confident (%)	Very Confident (%)
44.8	43.1	12.1

18. The prevalence of ASD has increased over the past 10 years.

Really Don't Know (%)	Wrong (%)	Correct (%)
34.5	15.5	50

Not at all Confident (%)	Confident (%)	Very Confident (%)
48.3	43.1	8.6

19. All people with ASD are extremely impaired and cannot live independently as adults.

Really Don't Know (%)	Wrong (%)	Correct (%)
6.9	0	93.1

Not at all Confident (%)	Confident (%)	Very Confident (%)
6.9	29.3	63.8

20. There is a wide range of severity among individuals with ASD.

Really Don't Know (%)	Wrong (%)	Correct (%)
6.9	1.7	91.4

Not at all Confident (%)	Confident (%)	Very Confident (%)
12.1	36.2	51.7

21. Most scientists and doctors know what causes ASD.

Really Don't Know (%)	Wrong (%)	Correct (%)
32.8	5.2	62.1

Not at all Confident (%)	Confident (%)	Very Confident (%)
36.2	41.4	22.4

22. The diagnosis of ASD varies by race/ethnicity.

Really Don't Know (%)	Wrong (%)	Correct (%)
46.6	25.9	27.6

Not at all Confident (%)	Confident (%)	Very Confident (%)
60.3	32.8	6.9

23. Individuals with ASD often engage in restrictive, repetitive behaviours.

Really Don't Know (%)	Wrong (%)	Correct (%)
17.2	1.7	81

Not at all Confident (%)	Confident (%)	Very Confident (%)
34.5	44.8	20.7

24. Individuals with ASD cannot show affection.

Really Don't Know (%)	Wrong (%)	Correct (%)
12.1	0	87.9

Not at all Confident (%)	Confident (%)	Very Confident (%)
22.4	46.6	31

25. There is a specific gene that can be used to identify ASD.

Really Don't Know (%)	Wrong (%)	Correct (%)
55.2	8.6	36.2

Not at all Confident (%)	Confident (%)	Very Confident (%)
67.2	24.1	8.6

26. Some individuals with ASD have trouble tolerating loud noises or certain types of touch.

Really Don't Know (%)	Wrong (%)	Correct (%)
6.9	0	93.1

Not at all Confident (%)	Confident (%)	Very Confident (%)
6.9	46.6	46.6

27. Individuals with ASD rarely form intimate relationships, even with their parents.

Really Don't Know (%)	Wrong (%)	Correct (%)
22.4	10.3	67.2

Not at all Confident (%)	Confident (%)	Very Confident (%)
36.2	44.8	19

28. Because of their lower social awareness, individuals with ASD rarely have anxiety disorders.

Really Don't Know (%)	Wrong (%)	Correct (%)
12.1	3.4	84.5

Not at all Confident (%)	Confident (%)	Very Confident (%)
19	50	31

Based on Table 23, items with the lowest and highest percentages of correct responses, items with the highest percentages of 'Really Don't Know' or 'Wrong' responses, as well items with the highest percentages of 'Not at all Confident' and 'Very Confident' are presented.

Table 23 shows that the item with the lowest percentage of correct answers was statement 12 which was '*One common treatment for ASD is Dialectical Behaviour Therapy'* with only 17.2% (N = 10) of respondents getting the answer correct. The next lowest scoring statement was 22 which was *'The diagnosis of ASD varies by race/ethnicity'* with only 27.6% (N = 16) of participants answering correctly. The third lowest scoring statement was 11, which was '*Many individuals with ASD have trouble sleeping'* with only 34.5% (N = 20) getting the answer correct.

On the other hand, the highest scoring statements were 1, 19 and 26 which were all answered correctly by 93.1% (N = 54) of participants. Statement 1 was '*Adults can never be diagnosed with ASD',* statement 19 was '*All people with ASD are extremely impaired and cannot live independently as adults'* and statement 26 was '*Some individuals with ASD have trouble tolerating loud noises or certain types of touch'.*

It is also important to highlight items which had high responses of 'Really Don't Know' or 'Wrong' as this indicates areas of lacking/incorrect knowledge. The three statements with the highest percentages of Really Don't Know responses were statements 25, 16 and 15. Statement 25 was *'There is a specific gene that can be used to identify ASD',* statement 16 was *'Many scientists believe that ASD is a product of abnormal brain development',* and statement 15 was '*Problems during birth (e.g. foetal distress, breech presentation) have been linked to ASD'.* For statement 25, 55.2% (N = 32) of participants reported they really did not know the answer, for statement 16 this percentage was 51.7% (N = 30) and for statement 15, 48.3% (N = 28). The three statements with the highest percentages of Wrong responses were statements 12 (*One common treatment for ASD is Dialectical Behaviour Therapy),* 2 (*There is currently no medical test to diagnose ASD*), and 6 (*The biggest problem with diagnosing ASD is that symptoms do not appear until age five or older).* The percentage of 'Wrong' responses for statement 12 was 39.7% (N = 23), with a percentage of 27.6% (N = 16) for both statements 2 and 6.

In relation to confidence, the three statements with the highest 'Not at all Confident' responses (indicating lacking confidence) were statements *16, 15 and 25.* These were also the three statements with the highest responses of 'Really Don't Know' in relation to ASD knowledge, as discussed above. For statement 16, 70.7% (N = 41) of participants reported they were Not at all Confident, 25.9% (N = 15) reporting they were Confident, and only 3.4% (N = 2) stating they were Very Confident. In relation to statement 15, 69% (N = 40) reported they were Not at all Confident, 27.6% (N = 16) stated they were Confident, and again only 3.4% (N = 2) stated they were Very Confident'. Thirdly, for statement 25, 67.2% (N = 39) reported that they were Not at all Confident, 24.1% (N = 14) stated they were Confident, and 8.6% (N = 5) were Very Confident in their response.

Contrastingly, statements with high responses of Very Confident were statements 19, 20, 26 and 1, with statements 26 and 1 both having the same number of 'Very Confident' responses. For statement 19, '*All people with ASD are extremely impaired and cannot live independently as adults',* 63.8% (N = 37) stated they were Very Confident in their response, with 29.3% (N = 17) stating they were Confident and 6.9% (N = 4) reporting they were Not at all Confident. The statement with the second highest number of Very Confident responses was statement 20, '*There is a wide range of severity among individuals with ASD',* with 51.7% (N = 30) of participants stating they were Very Confident, 36.2% (N = 21) reporting they were Confident, and 12.1% (N = 7) stating they were Not at all Confident in their response. For both statements 26 '*Some individuals with ASD have trouble tolerating loud noises or certain types of touch'* and 1 '*Adults can never be diagnosed with ASD',* 46.6% (N = 27) reported they were Very Confident in their response to the statement. For statement 26, 46.6% (N = 27) reported they were Confident, with 6.9% (N = 4) stating they were Not at all Confident. For statement 1, 41.4% (N = 24) stated they were Confident with 12.1% (N = 7) reporting they were Not at all Confident in their response. It is interesting to note that statements 19, 26 and 1, that had high responses of Very Confident, were also the three statements with the highest number of correct responses in relation to knowledge.

7.4.6 Testing for Normality

Before the undertaking of inferential statistical analyses, the distribution of the scores were investigated using the Shapiro-Wilk test, a test of normality. A Shapiro-Wilk test explores whether a distribution of scores varies significantly from a normal distribution (Field, 2018). Scores for the individual scales were analysed separately. When exploring distribution for the ASD knowledge scale, a Shapiro-Wilk test showed a significant departure from normality, $W(58) = .84$, $p < .001$. This means that the ASD knowledge scale was found to have a non-normal distribution of data as shown in Figure 7 with a visible positive skew of scores.

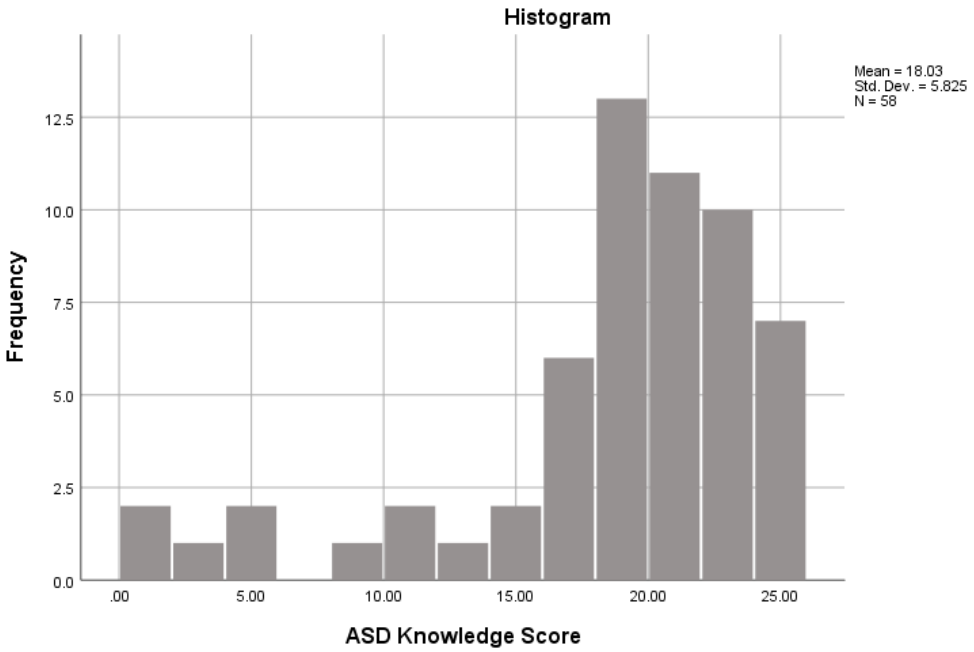

Figure 7: Histogram illustrating deviation from a normal distribution on the ASD knowledge scale

When exploring distribution for the ASD confidence scores, a Shapiro-Wilk test showed a non-significant departure from normality which demonstrates the scores were normally distributed, $W(58) = .97$, $= p = .14$. Figure 8 shows the normal distribution of the ASD confidence scores.

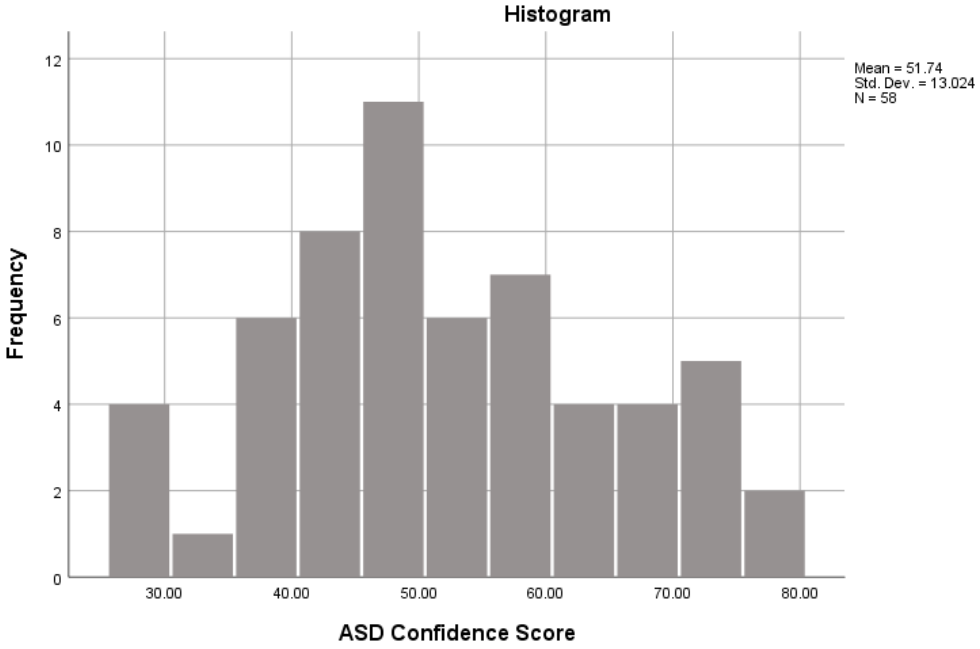

Figure 8: Histogram illustrating the normal distribution of the ASD confidence scale

The above Shapiro-Wilk tests informed the statistical analyses to be undertaken on the data. When undertaking the inferential analyses, non-parametric tests were used when examining the ASD knowledge scores, and parametric tests were utilised for the ASD confidence scores. Non-parametric tests are used instead of parametric tests when the data is not normally distributed. When a correlation analysis was required to examine the relationship between the two dependent variables [ASD knowledge and ASD confidence scores], a non-parametric test was used. The non-parametric tests used were: one-sample Wilcoxon signed rank tests, a Spearman's Rho and Kruskal-Wallis tests. A one-way Analysis of Variance (ANOVA) was the parametric test utilised for analysis. The post hoc tests undertaken were Bonferroni and Mann-Whitney U.

7.5 Inferential Statistics

7.5.1 Hypothesis 1

Hypothesis 1: Mental health professionals will have good knowledge of ASD.

When NHS staff are required to undertake staff training on the NHS Electronic Staff Record (ESR), a score of 80% is required to pass online learning modules. Therefore, this research utilised a score of 80% as the score required for 'good' knowledge. To explore hypothesis 1, a one-sample Wilcoxon signed rank test was undertaken to determine whether the median of the data for ASD knowledge (19) was statistically equivalent to a score of 80% (22.4) on the questionnaire. The results of the analysis did not support hypothesis 1, as the analysis found that the median of the data was significantly different from an ideal score of 80% on the questionnaire, with a p-value $< .001$ (see Appendix 26). This means that the hypothesis, mental health practitioners will have good knowledge of ASD, was not accepted. This finding was further explored by looking at ASD knowledge in the different occupation groups (Therapies, Social Care, and Nursing). Please see the following table (Table 24) to see the number of participants and median for each occupation group.

Table 24: Number of participants and medians by occupation group

Occupation Group	N	Median
Therapies	22	22
Social Care	11	18
Nursing	25	18
Total	**58**	**19**

A one-sample Wilcoxon signed rank test was undertaken for each occupation professional group, comparing the group median to an ideal score of 80% (22.4). For Therapies, there was no significant difference between the median (22) and ideal score of 80% (22.4), with a p-value of .10 (see Appendix 27). For Social Care, a significant difference was found between the median of 18 and an ideal score of 80% (22.4), with a p-value of .033 (see Appendix 28). A significant difference was also found for Nursing, between the median of 18 and an ideal score of 80% (22.4), with a p-value less than .001 (see Appendix 29). This highlights differences in the ASD knowledge scores obtained by the different occupation groups. This is further explored under Hypothesis 3.

7.5.2 Hypothesis 2

Hypothesis 2: There will be a relationship between ASD knowledge and ASD confidence.

To explore hypothesis 2, a Spearman's Rho was undertaken to measure the strength of the association between ASD knowledge and ASD confidence. A non-parametric test was used due to the ASD knowledge scale being non-normally distributed. This revealed a moderate (verging on strong) positive correlation between ASD knowledge scores and ASD confidence scores, which was statistically significant, r_s = .69, p = .000 (see Appendix 30). A visual representation of the positive correlation is presented in Figure 9.

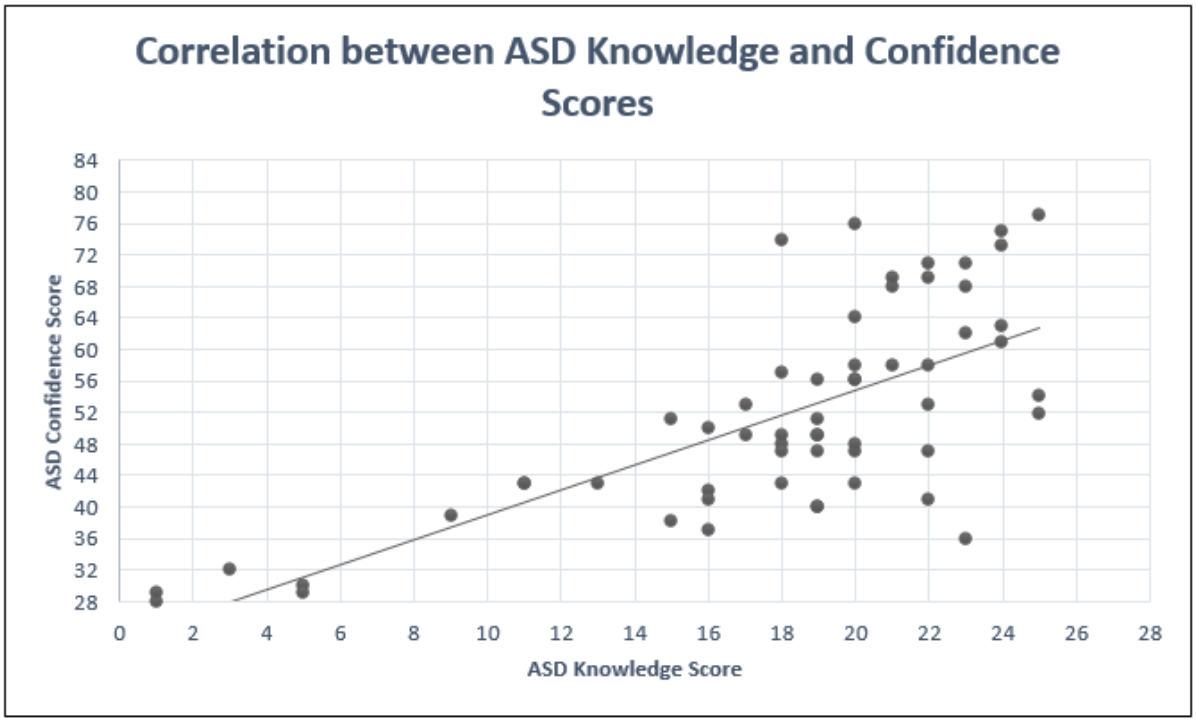

Figure 9: Illustration of the moderate positive correlation found between ASD knowledge and confidence scores

This positive correlation suggests that as ASD knowledge scores increase, so do ASD confidence scores (and vice versa). It also suggests that those with lower ASD knowledge scores, will have lower ASD confidence scores. The finding of a positive correlation supports Hypothesis 2, that 'there will be a relationship between ASD knowledge and ASD confidence'. Therefore, the null hypothesis, that there would be no association between the two variables, was rejected.

7.5.3 Hypothesis 3

Hypothesis 3: ASD knowledge will vary by occupation group.

A Kruskal-Wallis test was undertaken to determine if there were statistically significant differences in ASD knowledge scores between the three occupation groups (Therapies, Social Care, and Nursing). The Kruskal-Wallis test revealed that were was a statistically significant difference in ASD knowledge score between the different occupation groups, $H(2) = 13.51$, $p = .001$, with a mean rank score of 39.84 for Therapies, 24.59 for Social Care, and 22.56 for Nursing (see Appendix 31). Therapies professionals scored higher on ASD knowledge (Mdn = 22) than professionals from Social Care (Mdn = 18) and Nursing (Mdn = 18). The above findings support Hypothesis 3, and as such the null hypothesis that ASD knowledge will not vary by occupation group, can be rejected.

Post-hoc Mann Whitney U tests compare differences between two independent groups and were utilised to compare the three occupation group pairs. When examining Therapies and Social Care, ASD knowledge scores were significantly greater for Therapies than for Social Care, $U = 69$, $p = .05$ (see Appendix 32). For Therapies and Nursing, ASD knowledge scores were significantly higher for Therapies than for Nursing, $U = 99.5$, $p < .001$ (see Appendix 33). However, no significant difference in ASD knowledge scores were found between Social Care and Nursing, $U = 135.5$, $p = .945$ (see Appendix 34). From this data, it can be concluded that ASD knowledge scores were significantly higher for Therapies than for both Social Care and Nursing, with no significant difference in ASD knowledge scores found between Social Care and Nursing.

7.5.4 Hypothesis 4

Hypothesis 4: ASD confidence will vary by occupation group.

A one-way Analysis of Variance (ANOVA) was undertaken to compare the effect of occupation group on ASD confidence scores. This revealed a statistically significant difference in ASD confidence scores between the three occupation groups ($F(2,55) = 8.77$, $p < .001$) (see Appendix 35). This supports Hypothesis 4, that ' ASD confidence will vary by Occupation Group', therefore the null hypothesis, that ASD confidence will not vary by occupation group, can be rejected.

Bonferroni post hoc tests were used to compare all occupation group pairs to confirm where differences occurred between the occupation groups (see Appendix 36). Confidence scores were significantly higher for Therapies (Mean = 59.86) when compared to Social Care (Mean = 46.82) ($p = .01$). A significant difference in ASD confidence scores was also found between Therapies and Nursing (Mean = 46.76) ($p = .001$). No significant difference in ASD confidence score was found between Social Care and Nursing ($p = 1.00$). The above findings indicate that professionals from Therapies have significantly higher confidence in their ASD knowledge than professionals from both Social Care and Nursing.

7.5.5 Hypothesis 5

Hypothesis 5: ASD knowledge will be higher for those that have received ASD training compared to those who have not.

A Kruskal-Wallis test was undertaken to determine if there was a statistically significant difference in ASD knowledge scores between staff who had received ASD training and those who had not. A statistically significant difference was found in ASD knowledge scores between the two groups, $H(1) = 8.23$, $p = .002$, with a mean rank score of 37.04 for those who had ASD training, and a mean rank score of 24.18 for staff who had not received ASD training (see Appendix 37). The mean score for those who had received ASD training was 20.54 (N = 24) compared to 16.26 (N = 34) for those who had not. The median ASD knowledge score for those who had received ASD training was 21.5, compared to 19 for professionals who had not received training. The above findings support Hypothesis 5, as ASD knowledge scores were found to be significantly higher for staff who had received ASD training compared to those who had not.

7.5.6 Hypothesis 6

Hypothesis 6: ASD confidence will be higher for those that have received ASD training compared to those who have not.

A one-way ANOVA was undertaken to compare the effect of ASD training on ASD confidence scores. A statistically significant difference in ASD confidence scores between the two groups was found ($F(1,56) = 23.73$, $p < .001$) (see Appendix 38). The mean ASD confidence score for those who had received ASD training was 60.13 (N = 24), compared to 45.82 (N = 34) for those who had not received ASD training. The findings of the ANOVA support Hypothesis 6 as significantly higher ASD confidence scores were found in the group of professionals who had received ASD training.

7.6 Overview of Quantitative Results

A variety of parametric, non-parametric, and post hoc tests were undertaken to answer the research hypotheses. Table 25 visually illustrates which research hypotheses were supported by the statistical analyses, and which hypothesis was not.

Table 25: Table showing research hypotheses with corresponding findings

Hypothesis 1	Mental health professionals will have good knowledge of ASD.	Not supported
Hypothesis 2	There will be a relationship between ASD knowledge and ASD confidence.	Supported
Hypothesis 3	ASD knowledge will vary by occupation group.	Supported
Hypothesis 4	ASD confidence will vary by occupation group.	Supported
Hypothesis 5	ASD knowledge scores will be higher in those that have received ASD training compared to those who have not.	Supported
Hypothesis 6	ASD confidence scores will be higher in those that have received ASD training compared to those who have not.	Supported

Hypothesis 1 was the only hypothesis that was not supported. The results indicate that as a whole, mental health professionals do not have a good knowledge of ASD, with 'good' being deemed as a score of 80%. However, group differences were identified, with Therapies having higher ASD knowledge scores than both Social Care and Nursing.

In relation to Hypothesis 2, a moderate positive correlation was found between ASD knowledge scores and ASD confidence scores. This means that professionals with higher ASD knowledge tended to be more confident in their ASD knowledge, and individuals with lower ASD knowledge had less confidence.

For Hypothesis 3, a significant difference was identified in ASD knowledge scores between the three occupation groups. Post hoc tests revealed that ASD knowledge scores were significantly greater for Therapies compared to both Social Care and

Nursing. No significant difference in ASD knowledge scores was found between Social Care and Nursing.

With regards to Hypothesis 4, ASD confidence scores were found to significantly differ between the three occupation groups. Post hoc tests revealed that Therapies had significantly higher ASD confidence scores when compared to both Social Care and Nursing. However, no significant difference in ASD confidence scores was found between Social Care and Nursing.

For hypothesis 5, ASD knowledge scores were found to be significantly higher for staff who had undertaken ASD training compared to professionals that had not received ASD training.

In relation to hypothesis 6, significantly higher ASD confidence scores were found in the group of professionals who had received ASD training compared to professionals who had not received ASD training.

7.7 Summary

This chapter has presented the findings of the descriptive and statistical analyses undertaken on the staff questionnaire. The chapter provided six research hypotheses, and the results from descriptive and inferential statistics were presented. Five of the six research hypotheses were supported by the findings. The hypothesis that was not supported was Hypothesis 1, 'Mental health professionals will have good knowledge of ASD'. The chapter that follows will bring together and discuss the findings of both Phase 1 and Phase 2 in relation to the study's specific research questions, and in the context of existing literature.

Chapter Eight: Discussion

8.1 Introduction

This chapter will bring together the findings of Phase 1 and Phase 2 to address the aims of the research. The findings of the current study will be discussed, making reference to existing literature and current clinical guidance, showing how the findings add to current understanding. This study obtained rich, qualitative data about the experiences of adults with autism accessing mental health services, as well as quantitative data to establish mental health professionals' current level of ASD knowledge. The findings of Phase 1 will be provided and discussed prior to the results of Phase 2.

8.2 Phase 1

Interpretative Phenomenological Analysis (IPA) was used to explore the mental health service needs of adults with autism. The findings of this analysis highlighted 5 superordinate themes: Experience of Autism Diagnosis, Staff Awareness of Autism, Facilitating Communication, Dissatisfaction, and Making Accommodations. These superordinate themes will now be discussed in turn, whilst incorporating current clinical guidance and the findings of existing literature.

8.2.1 Superordinate Theme 1: Experience of Autism Diagnosis

The superordinate theme, Experience of Autism Diagnosis, illustrated participants' experiences of their autism diagnostic journey from the beginning to the end, and also captured the negative impact that was experienced for those who were diagnosed with autism later in life. Several participants reflected on their experiences of being assessed for autism, with participants having very different experiences of assessment. One participant was diagnosed following a single session, with some participants having several assessment sessions and completing numerous assessments. This indicated that the assessment process for autism was inconsistent, with different professionals undertaking varying approaches to assessment. Very limited research has been undertaken exploring the experiences of adults with autism of being assessed for, and diagnosed with autism. Exploring this topic, Jones et al. (2014) using an online questionnaire (N= 128), found that 34 participants were

diagnosed at their initial visit, 40 were diagnosed at their first referral, with 54 requiring subsequent referrals. Of these, 26 participants received their ASD diagnosis on the third referral, 11 on the fourth referral, 7 diagnosed on the fifth referral, with 10 having to attend six or more referrals before being diagnosed with ASD. Jones et al. (2014) found it took participants on average 2 years to get an ASD diagnosis after seeking professional help. A finding of the current study, that the experience of the assessment process can vary greatly from one person to another, was consistent with the findings of Jones et al. (2014). It must be considered that the varying assessment experiences reported may be a reflection of the diversity of individuals on the spectrum, with women with autism potentially presenting very differently to men with autism; the diversity and complexities of ASD require professionals to undertake thorough assessment as there is not a biological test to confirm ASD. However, for people who are fighting to obtain an autism diagnosis, the diagnostic process may cause frustration and a delay in receiving support.

The way in which participants were informed of their autism diagnosis was discussed by several participants who believed the way in which the diagnosis was communicated to them was ambiguous. For some participants, they were not even aware they had been given the diagnosis and were left unsure. A need for autism diagnoses to be communicated in a clear and comprehensible way was evident. At present, there appears to be no concrete guidance available which details how a professional should specifically communicate an autism diagnosis to a service user. This could in turn lead to inconsistencies in how diagnoses are shared. The NICE (2011) guideline relevant to service user experience in adult mental health services states that professionals should discuss and provide written materials about the nature of the condition that the service user had been diagnosed with, and professionals should also ensure that pertinent treatments and services are discussed with the service user. This is supported specifically in relation to ASD by the NHS (2019b), who stated that following an ASD assessment, individuals should be given a written report communicating the outcome of an assessment, confirming whether or not the individual has been given an ASD diagnosis. This report should also highlight areas that the individual might need support with and should also highlight the strengths of the individual (NHS, 2019b). The way in which diagnoses are shared with service users is of importance, as Jones et al. (2014) found individuals' perception of the

quality of information given to them at diagnosis was the most significant predictor of overall satisfaction with the diagnostic process.

For the majority of participants, receiving their autism diagnosis was a positive outcome for them. This finding is supported by Jones et al. (2014) who found that 85.9% of their participants (N=110) were glad they had received their ASD diagnosis. Participants in their study were asked to select emotions that they felt on hearing their diagnosis; the most common response was 'relief' (71.9%, N=92), however some participants also reported negative emotions such as 'anxious' (25%, N=32), 'confused' (24.2%, N=31) and 'upset' (17.2%, N=22). Beresford et al. (2020) found a similar finding whereby the predominant emotional response to receiving an autism diagnosis was a sense of relief, although many participants experienced a mixed set of emotions following the initial sense of relief. Reasons why participants felt relieved included: having their suspicions confirmed, having an explanation for the difficulties they have experienced, and also that their life-long difficulties had been validated (Beresford et al., 2020). The findings of the current study resonated with the findings above; participants reported that the autism diagnosis made sense to them, the diagnosis made a difference, the diagnosis answered questions they had, and provided a sense of relief. However, one participant did highlight that although the autism diagnosis explained a lot of things for her, receiving the diagnosis did not take away her depression, and therefore a need for a holistic approach was proposed. The above evidence suggests that individuals can react differently when receiving their autism diagnosis; although most participants in both the current study and previous studies found the diagnosis to be a positive outcome, some may experience negative feelings about an ASD diagnosis. This suggests a need for post-diagnostic support to allow individuals to come to terms with their new diagnosis, and understand what having a diagnosis of autism means to them.

After receiving a diagnosis of autism, a need for support was evident, with several participants perceiving the support given to them post-diagnosis to be inadequate or non-existent. Some participants portrayed a sense of abandonment/isolation following their diagnosis, recalling not even being given resources to read and there being no follow-up. According to NICE (2016) guidance, all adults should be offered a follow-up appointment post-ASD diagnosis to discuss the implications of the diagnosis, to address any queries the individual may have, and to consider future support that the

service user may require. In line with NICE guidance, the Welsh Government's (2016b) Refreshed Autistic Spectrum Disorder Strategic Action Plan contended that individuals with autism should have access to a post-diagnostic service which meets the individual's needs. The findings of the current study would suggest that not all service users are offered a post-diagnosis follow-up, which is consistent with the findings of Jones et al. (2014) who found that 41.9% of their respondents were offered no form of post-diagnostic support. According to their study, counselling, social skills training and access to support groups were participants' three most cited types of support that they would have liked to have received post-diagnosis. A participant in the current study also expressed a desire for counselling to help them come to terms with the new autism diagnosis. In relation to post-diagnostic support, Beresford et al. (2020) compared the experiences of individuals who had been given only a follow-up session after receiving their autism diagnosis to individuals who had accessed psychoeducation following diagnosis. It was found that participants spoke very highly of the psychoeducational support, whereas individuals who had only received the follow-up session felt the support had been insufficient, leaving participants feeling abandoned. Some of the participants in the current study reported receiving no post-diagnostic support, and in concurrence with the findings of Beresford et al. (2020), this led to feelings of abandonment and isolation. Also worth noting, participants reported the sharing of written materials to be of limited value and a belief that using the internet to find further information was risky (Beresford et al., 2020). None of the participants in Beresford et al.'s (2020) study had reached out to signposted services; this may be due to the fact that participants required support to access the signposted services (a finding of the current study).

The impact of receiving an autism diagnosis later in life was discussed by several participants in the current study. A sense that things could have been different if the autism had been identified earlier was present, as well as beliefs that mental health difficulties may have been prevented if the autism was diagnosed sooner. Beresford et al. (2020) found similar findings with participants reporting notions of frustration that their autism was not identified sooner, and a sense of grief over the years that they had lost when they were not aware of their autism. This finding was also echoed by Leedham et al. (2020) who found that participants portrayed a sense of sadness for their self pre-diagnosis, and considered how the struggles they had experienced could

have been minimised if their needs had been understood earlier. Beresford et al. (2020) also found that interviewees could not understand how their autism had not been detected sooner even when they had been accessing professionals/services for so many years; this frustration and confusion was also felt by several participants in the current study.

8.2.2 Superordinate Theme 2: Staff Awareness of Autism

The second superordinate theme, Staff Awareness of Autism, conveyed participants' belief that professionals should have knowledge and understanding of autism, and that this knowledge can result in more positive professional-service user interactions. The majority of participants highlighted the need for professionals to have autism knowledge, and professionals having an awareness of masking was viewed as particularly important in order to improve the detection of undiagnosed adults. However, current levels of autism knowledge were felt to be inadequate. This finding supports Crane et al. (2018), with interviewees in their study expressing concerns that professionals might not have sufficient levels of expertise and knowledge of autism. Bradshaw et al. (2019) also found a lack of provider knowledge and training to be a provider-level factor in their review. NICE (2016) guidelines state that all health professionals providing care and support to adults with autism should have a broad understanding of: the nature, development and course of autism, the impact of autism on an individual's functioning, the impact of social and physical environments on individuals with autism, and the impact of co-existing mental and physical disorders. The findings of the current study, and above mentioned literature, would suggest that not all health professionals have the level of autism knowledge recommended by NICE. Additionally, several participants in the current study stated that some professionals held misconceptions about autism, or had knowledge about autism that was incorrect. Similarly, participants in a study undertaken by Nicolaidis et al. (2015) also raised concerns that providers would hold misconceptions or believe myths about autism. This highlights a need for professionals to have an accurate and up-to-date knowledge and understanding of autism. Training was highlighted by several participants as a means of improving the autism knowledge of professionals. Autism training for professionals was advocated for in several studies in order to improve the healthcare experience for adults with autism (Nicolaidis et al., 2015; Camm-Crosbie et al., 2018; Bradshaw et al., 2019); Barber (2017) contended that active participation

in autism training should be mandatory in order to provide appropriate services to this population. However, it must be acknowledged that better knowledge does not automatically translate into better service user experiences; other factors are at play such as service constraints and service funding, the individual professional(s), and duration and type of support offered/provided.

The impact of professionals' knowledge of autism on service user experience was evident in the current study; professionals having autism knowledge seemed to result in a more positive service experience for service users. This finding was supported by Nicolaidis et al. (2015) who concluded that patients' healthcare experience largely depended on providers' knowledge, skill, attitudes and behaviours in working with adults with autism (areas in which training was recommended). Additionally, Camm-Crosbie et al. (2018) identified a lack of understanding and knowledge as a theme in their study, with this theme emerging from participants' negative interactions with professionals who lacked autism knowledge. Higher levels of autism knowledge in professionals was associated with a more positive experience of support; autism knowledge resulted in participants feeling understood and valued. The concept that higher levels of autism knowledge contributes to better support for service user was supported by Barber (2017), with a participant stating "I believe that without such an awareness and understanding they would not be able to fully meet my health needs" (p.422). Further support was provided by Beresford et al. (2020) who highlighted the role that professionals' autism expertise has in delivering services that meet the needs of their clients. In fact, Bradshaw et al. (2019) contended that professionals who lack autism knowledge, training and confidence in autism can result in barriers to accessing appropriate care, and can result in autism being missed in adults. This argument is echoed in the findings of the current study whereby participants contended that better autism knowledge would allow for better detection of undiagnosed adults with autism and could prevent service users' difficulties being wrongly attributed to mental health conditions.

Additionally, a need for professionals to have an awareness of masking was evident in the current study. Several participants reported masking when accessing mental health support; participants discussed how hard it can be to drop the mask, which could potentially result in a late diagnosis of autism. This finding was supported by Crane et al. (2019), with participants reporting years of hiding their true selves due to

a pressure to act 'normal' in a neurotypical world; they felt that this resulted in delays in receiving a formal diagnosis of ASD. Hull et al. (2017) reported that camouflaging/masking may lead a health professional to believe that an individual is functioning well and is not experiencing difficulties, when that might not be the case. This finding was present in the current study, with masking potentially disguising the actual difficulties being experienced by service users. It was proposed by Mandy (2019) that masking can conceal an individual's difficulties which can then prevent them from being understood and helped; not surprisingly, masking can delay or even prevent an ASD diagnosis. A participant in the current study emphasised the toll that masking can take; this again was supported by Crane et al. (2019) who found that many participants felt that their mental health problems resulted from a pressure to be 'normal'. Beck et al. (2020) supported this argument, finding camouflaging behaviours to be significantly associated with psychological distress. Therefore, it appears that a need for professionals to have an awareness of masking in autism is required in order to support the better detection and support of adults with undiagnosed autism.

8.2.3 Superordinate Theme 3: Facilitating Communication

The third superordinate theme, Facilitating Communication, captured ways in which communication could be utilised to best serve the needs of service users. It was suggested that negative interactions between service users and professionals can dissuade participants from seeking help in the future. This evidences the need for successful professional-service user encounters. A need for improved communication between and within the service was also evident. All participants in the current study shared their experiences of communicating with professionals; a mix of both positive and negative interactions were disclosed. Several participants conveyed a need to talk/offload to a mental health professional; participants discussed the benefit of discussing their feelings and the negative consequences of suppressing them. Mind (2011) found that respondents in their study indicated that having someone to talk to, and being given that time to talk was vital in times of crisis. A need for the professional offering this support to be respectful, warm, compassionate and understanding was also identified (Mind, 2011) The importance of service users feeling listened to by professionals was also highlighted by Tint and Weiss (2017) who found that participants valued being listened to by professionals, and appreciated feeling heard when others were willing to listen. A need for professionals to listen to the content of

what the service user is saying was evident in the current study; participants wanted professionals to listen rather than assume. Nicolaidis et al. (2015) found providers' incorrect assumptions about a patients' skills or needs to be a common explanation for why participants had felt that they had received poor care or had a negative healthcare experience. In addition to a need to talk to professionals and be listened to, participants conveyed a need for professionals to communicate with service users in a clear and direct manner. Relevant to clear communication, Dern and Sappok (2016) highlighted 'general difficulties in verbal and nonverbal communication' and a 'literal understanding of language' to be barriers to healthcare for adults with autism; recommendations to help overcome these barriers included: avoiding open questions, offering choice among options, giving time for questions/answering, choosing few words, using simple and exact language, staying concrete, and avoiding irony, figures of speech and jokes. Participants discussed professional characteristics they thought to be desirable; for example, being kind, caring, friendly, approachable, attentive, authentic and compassionate. Service users reported that professionals who possessed these characteristics made service users feel valued and comforted which enhanced rapport. Relevant to rapport, Crane et al. (2018) explored how comfortable service users felt with sharing their mental health difficulties with professionals; only 3 participants in their study felt extremely comfortable to discuss their difficulties. This indicates a need for improved rapport; participants' views would suggest that if professionals displayed the desired professional characteristics, it could help to improve rapport, which could in-turn result in improved comfort to share their mental health difficulties. Participants specifically discussed negative interactions they had experienced with professionals; it was suggested that negative experiences could deter service users from seeking help in the future. Bradshaw et al. (2019) also found previous negative experiences in healthcare to be a significant barrier to accessing care; this highlights the importance of having successful healthcare encounters.

Relevant to communication, the majority of participants in the current study communicated a strong dislike for phone calls, with a preference for the health board contacting them through written means. This indicates that both the content and mode of communication is important when making support accessible to service users with autism. Participants found phone calls, particularly when not expected, to be anxiety provoking with some participants finding it almost impossible to talk on the phone.

Dern and Sappok (2016) stated that adults with autism may find it difficult to make an appointment over the phone and suggested allowing this population to arrange their appointments in other ways, for example, via email. A need for alternatives to phone contact was also proposed by Bradshaw et al. (2019). Bradshaw et al. (2019) contended that service users may experience anxiety about arranging appointments due to difficulties with social interaction and making phone calls. Participants elaborated on their difficulties with phone calls; reasons included: difficulties with turn-taking when communicating via phone, a preference for having time to consider a response before replying to queries, and a dislike of sharing personal information with a stranger over the phone. Participants also suggested a desire for multiple forms of communication in relation to appointments, for example, sending an appointment letter followed by a text reminder closer to the appointment date. This approach could help to ensure that participants do not miss or forget appointments, resulting in a reduction of wasted clinician time and more effective support for people with autism.

Another finding of the current study was that the majority of participants had a dislike for ambiguity and/or uncertainty due to the anxiety it provokes; a desire for information and to feel informed was important to the participants. A need for professionals to take into account the importance of predictability, clarity, structure and routine for adults with autism is present within the NICE (2016) guidelines. Chaplin, Spain and McCarthy (2020) discussed intolerance of uncertainty as one reason as to why anxiety is so common in individuals with autism; intolerance of uncertainty is considered a negative reaction to uncertain situation which can result in a need for predictability, with individuals finding it difficult to cope with uncertainty (Chaplin, Spain and McCarthy, 2020). The concept of intolerance of uncertainty corresponds with participants' reports of finding ambiguity in mental health services difficult to tolerate. Consequently, there is a danger that a service that is meant to provide mental health support could in fact exacerbate mental health difficulties. Providing structure and predictability were highlighted by Maddox et al. (2019) as ways to facilitate access to services. Ways in which professionals could provide structure and predictability included: providing service users with a written agenda for sessions (following a similar structure each session), having a regular appointment slot, and the professional spending time with the patient prior to commencing any therapy explaining what to expect during therapy, and making any expectations clear to the service user. A desire for wanting to know

appointment/visit dates and times, as well as a desire to know what will be discussed in appointments in advance was evident in the current findings. Participants also wanted to know what professional they would be seeing, the professional's role, the duration of the appointment, and location of the appointment. Having information in advance can allow individuals to feel better prepared for sessions, and would help to alleviate the anxiety experienced by service users prior to appointments which could result in improved professional-service user interactions. Additionally, waiting lists were specifically discussed in relation to a need to reduce uncertainty. Participants highlighted a desire to be updated in relation to their progress on waiting lists; these updates would offer reassurance that service users had not been forgotten and would alleviate some of the uncertainty experienced.

Participants discussed getting frustrated at times due to the perceived disconnection between and within teams; a need for better communication was suggested to help overcome this disconnection. A need for service users' diagnoses to be shared with all staff members involved in a person's care was evident, as well as a need for improved communication between departments (such as between the GP and the Crisis Team, and between Primary and Secondary Care). One participant shared a positive experience whereby a professional from mental health services had supported the participant whilst on a ward for physical health reasons; this communication had led to a more positive healthcare experience for the participant evidencing the benefit of staff and services being better connected through successful communication. The concept of integrated care and fragmented care have been discussed in relation to services within the NHS. Integrated care is when all elements of a person's care are brought together in a way that is person-centred and co-ordinated (UK Government, 2015). On the other hand, fragmented care is when a person's care is disconnected, difficult to access and not centred on the service users' needs (UK Government, 2015); fragmented care arises when different professionals/services do not effectually work together. Specifically in Wales, *The Social Services and Well-being (Wales) Act 2014* made it a legal obligation for local authorities to promote the integration of health and social care. Integrated care can improve outcomes for service users by reducing confusion, repetition, delay, duplication, and preventing service users' getting lost in the system (UK Government, 2015). A lot of frustration felt by participants within the current study was related to confusion, duplication and delay associated with

fragmented care. Services should be delivering integrated care, with individual healthcare professionals having a duty of care to service users which includes a need to share information to support their care (National Health Service X, 2021). The need for collaborative working and information sharing within MDTs was discussed by NHSX (2021) who contended that care being delivered in an integrated way enables care to be more efficient and effective. The need for better communication both at an individual level and service level was evident in the current findings, with UK Government (2015) and NHSX (2021) guidance supporting the importance of this in care services.

8.2.4 Superordinate Theme 4: Dissatisfaction

Dissatisfaction, the fourth superordinate theme, mainly encompassed elements of mental health services that service users were not fully satisfied with. Although the focus of this theme is predominantly on areas with room for improvement, the final subordinate theme within Dissatisfaction captured participants' gratitude to the service, with several participants attributing their life to mental health services. The majority of participants shared feeling frustrated with the way medication is prescribed by mental health services. Several participants felt professionals prescribed them medication as it was the easier option, rather than dealing with the underlying difficulties. A preference for other support options (such as talking therapies) was suggested by some participants. A review by McHugh et al. (2013) explored patients' preference for psychological versus pharmacological treatment for mental health disorders (not specific to autism) and found that approximately 75% of participants preferred a psychological treatment over taking psychiatric medication. Therefore, a desire to at least try alternatives to medication may not be specific to the adult autism population. A need to explore alternatives to medication is also discussed in the campaign titled STOMP (Stopping over medication of people with a learning disability, autism or both) which highlights the need to discuss both non-drug therapeutic options and practical ways to support individuals in order to reduce the need for medicine for people with autism (NHS, no date). A need for service users to be involved in decisions relating to their medication was highlighted in the current study; times when service users' views on medication had not been considered tended to result in negative experiences whereas situations where participants felt listened to by professionals led to more positive experiences. These findings correspond with the principles of person-

centred care whereby healthcare professionals and service users form a partnership to collaboratively determine what is important to the person, and to make decisions about the person's care (The Health Foundation, 2016). Specific to medication, NICE (2009) stresses the importance of good communication between the professional and patient in order to ensure that the service user is involved in decisions about their medication(s) (and to support adherence).

The idea that mental health services are reactive rather than proactive was suggested; several participants recalled becoming very mentally unwell (some in crisis) before being provided support. Participants believed that mental health services should have a more proactive and preventative role, with support being offered at an earlier stage in the hope of preventing crises. This finding resonates with NICE (2019) guidance which contends that timely access to mental health services is essential for the effective treatment of mental health conditions, and that timely access to support can help to prevent a person experiencing crises. In the current study, the concept of a cycle was proposed whereby service users are offered support at crisis point, then the person's mental health improves, all support is then withdrawn and then the person experiences another crisis, and so the cycle continues. A need for support to be available when needed (rather than only at crisis point) was suggested as a way to prevent the continuation of this cycle. Where participants reported having support available to them when needed (open appointments), this offered them comfort. The idea of a crisis-driven system was also discussed by Tint and Weiss (2017), with participants reporting difficulties in accessing support due to the reactive rather than preventative nature of the service. This finding is consistent with the current study, with participants reporting being unable to access preventative support. Pertinent to a preventative approach to support, WHO (2004) highlighted the need to pay greater attention to prevention and promotion in mental health at a variety of levels, from policy and legislation to decision making and resource allocation.

Within the current study, several participants believed the waiting lists to be too long, and the impact of long waits on participants' wellbeing was highlighted. Several existing studies acknowledged long waiting lists as a barrier to support (Crane et al., 2018; Camm-Crosbie et al, 2018; Bradshaw et al., 2019). One of the reasons cited for service users' needs not being met in the study undertaken by Beresford et al. (2020) was waiting times. This supports the findings of the current study, with waiting times

affecting participants' satisfaction with services. A clinical guideline published by NICE (2011) suggested that mental health services should offer individuals an appointment within 3 weeks of a GP sending a referral to the service. The findings of this study would suggest that this may not be happening in practice, with participants reporting large delays in accessing support. Additionally, participants in the current study stated that not knowing their progress in relation to the waiting list, and receiving no updates, caused them anxiety and frustration. Beresford et al. (2020) reported a similar finding, that a lack of contact from the team whilst waiting for the intervention to start caused some participants anxiety, fearing that they had been forgotten. This suggests a need to provide updates to service users whilst they are on waiting lists in order to alleviate anxiety.

For those participants who had accessed acute services, a general sense of dissatisfaction was reported in relation to both the Crisis Team and the mental health inpatient wards. In relation to the Crisis Team, several participants reported that they would not reach out to them if they were struggling as a result of previous negative experiences. Participants recalled experiences where they had felt dismissed by the team or believed that the care they received could have been better; several participants believed the Crisis Team to be unhelpful. According to the Care Quality Commission (2015), only 14% of people who have experienced a mental health crisis felt that the care they received helped to resolve it, with almost half of respondents not feeling confident that they would receive a helpful response in the future if they experienced another crisis. The report contended that a care system with such a low proportion of people believing that they can get help if they need it is inherently unsafe (Care Quality Commission, 2015). A need for the Crisis Team to be patient and compassionate, and to listen was evident, as service users' reaching out to this team may already be highly distressed. The Care Quality Commission (2015) explored service users' experiences of many services, including CRHTS, and found that 48% did not believe the CRHT has listened to their concerns and that 43% had felt they were not treated with warmth and compassion. This report suggested there appears to be a 50:50 chance as to whether individuals will receive crisis support that they value/need. It was contended that it is concerning that a service whose primary purpose is to support those in crisis do not appear to be meeting service users' expectations of compassionate care, with compassion being a core part of starting a

person on the road to recovery (Care Quality Commission, 2015). The Care Quality Commission's (2015) report was not specific to individuals with autism and therefore it may be the case that the findings in relation to CRHTs are a wider issue. In relation to the inpatient wards, two participants within the sample had previously had experience of the wards, and their experiences were primarily negative. Maloret (2019) also found the mental health inpatient experience of adults with autism to be generally poor and negative, with patients experiencing psychological effects of being an inpatient such as feeling anxious, distressed, angry and guilty. Service needs that arose specifically in relation to the wards are as follows: a need for staff to be available, a need for respectful communication with patients, and a need for physical health difficulties to be supported as well as mental health challenges. Specifically in relation to the availability of staff, a quality statement from NICE (2019) states that service users on mental health inpatient wards should receive daily one-to-one contact with professionals known to them, and that patients should regularly see other members of the MDT. The rationale for this is to help the patient: build trust and confidence, reduce worries and develop relationships. This quality statement suggests that patients should have dedicated one-to-one contact daily; a participant in the current study reported a lack of available staff to speak with which suggests that this quality statement may not currently be being met. The findings for both the Crisis Team and inpatients wards suggest that these services are currently not meeting the needs of adults with autism.

Participants in the current study contended that there is no clear pathway to assist service users with accessing support; the current process was described as vague and complex which led to service users feeling frustrated and exasperated. Existing literature has highlighted a lack of clear pathways as a barrier to care, with unclear/lacking pathways affecting the service experience of adults with autism (Crane et al., 2018; Bradshaw et al., 2019). A need for a clear pathway to enable service users to access services was proposed, as well as a need for a designated point of contact to reach out to in times of need. Crane et al. (2018) found that few participants reported feeling confident in knowing who to contact if they were experiencing difficulties, with even fewer respondents feeling confident that if they did seek help, that they would get appropriate support; this suggests a lack of confidence that services can meet service users' needs. The importance of having a named contact for service users was

also highlighted by Beresford et al. (2020) who found that all the participants in the 'needs met' group had received individualised managed care from a single member of staff who acted as the named contact for the service users. In the current study, participants believed that having a designated, consistent contact could prevent them from reaching crisis in the future as service users would know that support is available if and when required.

The idea that service users are falling through the cracks was evident in the findings. Several participants reported either being bounced around numerous services or that their care has been affected by the fact that they had co-existing conditions. In line with the findings of the current study, Maddox et al. (2020) found that participants experienced frustration due to not being accepted as clients by mental health providers due to their autism diagnosis. Additionally, Camm-Crosbie et al. (2018) also found that some of their participants felt that they fell through a gap in available services. From a clinician's perspective, Crane et al. (2019) found psychiatrists believed that mental health services are reluctant to work with individuals with autism; psychiatrists contended that there are very few professionals who feel confident in managing mental health difficulties in individuals with autism, and again the idea of a lack of co-ordinated mental health services for individuals with autism and mental health difficulties was proposed. It was contended by both clinicians and agency leaders that there is currently not a strong system in place for adults with autism with co-existing mental health needs (Maddox et al., 2020). Relevant to Wales, in recent years each health board has established an Integrated Autism Service (IAS) Team whose purpose is to provide support to individuals with autism. However, the IAS Team within the health board that is the focus of the current study does not offer direct support to adults with autism if they are in receipt of care and support from Mental Health or Learning Disability Services. This is another example of where participants could be bounced around services, struggling to access support. The findings of the current study and the above discussion suggests that service users with autism may be disadvantaged in relation to mental health support. A need for a service to take responsibility for adults with autism and co-existing mental health conditions was suggested.

Several of the participants had accessed CAMHS prior to AMHS, and there appeared to be significant inconsistencies in the transition process for these participants. Some participants reported a positive, smooth transition from service to service whereas

others had negative experiences which left them feeling let down by the service. One participant in particular was informed the service would be in touch and was unknowingly discharged from mental health services entirely rather than being transferred to AMHS; this participant had to refer herself back into mental health services. Poor transitioning from CAMHS to AMHS was highlighted as a barrier to support by Crane et al. (2018); the shift from a child-centred developmental approach in CAMHS to the adult-centred approach in AMHS was also discussed. This could result in a reduction of support at a time that is particularly challenging with healthcare transitions being a particular challenge for young adults with autism, especially those who have co-existing mental health difficulties (Crane et al., 2018). Murphy et al. (2016) argued that there remains a lack of clear pathways between child and adult services for individuals with autism. Participants' experiences suggested a need for there to be a more consistent, clear and equal process for the transition of services users from CAMHS to AMHS.

Several participants recalled times where they had been promised something by mental health professionals, and then that promise had never come to fruition. The impact of this was that the service users feel disappointed/let down by the professional, as well as by the service as a whole. A difficulty in dealing with people not keeping to their word was shared by participants. Barber (2017) highlighted that individuals with autism can have a very literal understanding of language; his advice to professionals was to "say what you mean and mean what you say" (p.422). For example, if a person with autism is offered counselling, they may take that offer as absolute truth, and then when the counselling is not provided, this could result in negative emotions such as sadness and anger for the person. Several participants specifically recalled times they had been offered a specific type of support (e.g. counselling) and they had never received it. A need for professionals to be clear, accurate and precise with their communication and explain what phrases like 'offered' means is evident. This theme demonstrated that professionals not following through on support they had offered to participants can lead to service users feeling misled and unimportant.

Although there were aspects of the mental health service that service users were dissatisfied with, the majority of participants expressed gratitude to the service. Several participants attributed their lives to the mental health service, stating that if it

was not for the service they would no longer be alive. Additionally, several participants praised professionals that had supported them during their time in mental health services. This theme captures the importance of mental health services and demonstrates the role it plays in maintaining service users' safety. A similar finding was found by Camm-Crosbie et al. (2018), with some participants sharing that they would no longer be alive, and that they would have succeeded in suicide, if it were not for the support they received. For other participants, support had enabled them to better function in the world, with life becoming more manageable (Camm-Crosbie et al., 2018). The findings of the current study and Camm-Crosbie et al. (2018) evidence the importance of mental health services for individuals with autism; for example, mental health services play a role in reducing risk (to the service user and potentially others) and aim to improve the quality of life for the service user. Although the service may not be perfect (as evidenced by the current superordinate theme), service users are still very grateful for the support they have received and still continue to receive.

8.2.5 Superordinate Theme 5: Making Accommodations

The final superordinate theme, making accommodations, conveyed areas in which accommodations could be made in mental health services in order to better meet the needs of the current population. A need for mental health services to make person-centred reasonable adjustments was discussed by Crane et al. (2019); they contended that these adjustments would help to ensure that people with autism and mental health conditions have equity of access/service compared to people without autism. However, as Barber (2017) highlighted, it is important to be aware than one size does not fit all even though many individuals with autism are likely to have similar healthcare issues, needs and expectations. In the current study, several participants shared that they have sensory sensitivities, and a need for environments to be accessible was highlighted. Participants discussed some of the difficulties they experienced which included lighting, temperature, acoustics and clocks (the sounds of clocks ticking or clocks not working). Using low-stimuli environments and avoidance of disturbing noises were suggested by Dern and Sappok (2016) as ways in which difficulties associated with sensory sensitivities can be eased. In addition, Maddox et al. (2019) found that adults with autism believed that clinicians did not accommodate for individuals' sensory aversions; a need for both professionals and the service as a whole to accommodate for sensory sensitivities was highlighted in the current study.

The waiting room environment was specifically highlighted as being challenging for participants; excessive posters on the walls, TVs playing, lighting and the layout of waiting room were highlighted by participants as elements of the waiting room they disliked. One participant suggested offering the option of an alternative, quieter waiting space which could help to alleviate service users' discomfort. Relevant to waiting spaces, Bradshaw et al. (2019) discussed waiting rooms in relation to service users' accessibility of healthcare facilities and advised minimising the time service users have to spend in waiting rooms due to the anxiety and discomfort they cause and recommended having a private waiting room available for service users if possible. NICE (2016) stressed the importance of taking into account the physical environment in which adults with autism will be seen in healthcare. They specifically recommended giving the person adequate personal space, ensuring walls and furnishings are a low-arousal colour (avoiding patterns), and a need to be mindful of lighting (e.g. reduce fluorescent lighting) and noise levels (e.g. reduce/minimise noise external to the room). Mind (2015) offered similar advice, but also encouraged professionals to carefully manage any changes to environment; consistency of the environment they argue is best, but if any changes need to be made, the person should be informed of these changes in advance. Although guidance conveys the importance of making adjustments, the *Equality Act 2010* places a legal duty on health services to make anticipatory reasonable adjustments for those with disabilities. Therefore, health services should be considering the guidance/information provided by NICE and other organisations as they identify areas in which adjustments will likely be required.

In addition to accessible environments, participants also stressed the importance of consistency, both in relation to having a consistent professional (rather than seeing lots of different professionals) and having regular and frequent appointments. It was suggested that consistency can contribute to continuity of care and a better service experience for service users. Nicolaidis et al. (2015) found patients' need for consistency to be an autism-related factor that affected their care. Additionally, Mind (2015) contended that having a regular venue, time and date is important for individuals with autism due to a need for routine, again highlighting the importance of consistency for adults with autism. One participant in the current study specifically discussed a dislike for not being informed of when professionals were going to arrive at her house for a home visit, and not knowing which professionals were going to

arrive; a need for service users to be informed was present. This need was supported by Nicolaidis who found providers' willing to consider accommodations to improve health interactions; examples of positive accommodations included: detailing what the process would be (descriptions of professionals and how long the process would take) and providing photos of staff members in advance. Offering consistent support to service users who are informed could lead to more positive healthcare experiences.

Participants portrayed a preference for certain types of support within the current study. For example, many participants stated they preferred one-to-one support rather than group delivered interventions. The NICE guideline (2016) acknowledged that some individuals with autism may find group-based activities (e.g. social learning programmes) difficult and suggested that these should be delivered on an individual basis for adults with autism. This suggests a need to tailor support to the needs/preferences of service users. Although many participants demonstrated a dislike for group delivered intervention, several participants discussed the benefit of attending an autism social group as a means to confer with other individuals experiencing the same challenges, and to obtain advice/information relevant to autism. Crompton et al. (2020) highlighted a need for social opportunities led by individuals with autism and suggested the benefit of peer support for adults with autism. They found that people with autism find spending time with other people with autism more comfortable and easier than spending time with neurotypical people. Participants within their study also reported feeling better understood by other people with autism and felt that they could be themselves around them. These findings resonate with the findings of the current study, suggesting the benefit to be had from attending autism social groups. Additionally, some participants also highlighted a need for there to be an alternative to verbal communication, such as allowing service users to communicate with professionals via writing. The importance of using accessible language was discussed by Nicolaidis et al. (2015) who found providers' unwillingness to allow patients to communicate in writing to be reported as a common reason as to why patients believed they had received poor care. Bradshaw et al. (2019) contended that if communication accommodations are not given (e.g. allowing the individual to communicate in writing or through visual means), barriers to communication may arise.

Finally, some participants recalled experiences where a mental health professional had acted as their advocate in order to ensure their needs were considered. An advocate acts as a patient's spokesperson; advocates can help service users to: understand the care process, talk about how they feel about their care, challenge decisions that they disagree with, and stand up for their rights as patients (NHS, 2018). The participants within this study generally recalled having a professional as their advocate to be a positive experience, with participants reporting that the professional gave them their own voice and understood their needs. However, one participant recalled an experience whereby wanting to bring a supporter to an appointment had led to delays in her care. Very little information is available in relation to the experiences of advocacy for adults with autism; although not a primary focus of this study, the findings suggest that mental health professionals can play an important role in ensuring that service users are listened to and considered in other settings (e.g. education and employment).

8.3 Phase 2

Quantitative analysis was undertaken to evaluate the knowledge and understanding of ASD held by mental health professionals in adult mental health services. This study specifically explored the ASD knowledge held by professionals working in adult mental health services (both primary and secondary), within a specific health board in Wales. To the best of the researcher's knowledge, this type of exploration has not been undertaken before and therefore the findings would be considered an original contribution to knowledge. The first hypothesis tested within this phase of the study was that 'mental health practitioners will have good knowledge of ASD'; the findings of the current study did not support this hypothesis and therefore the hypothesis was not accepted. Very limited existing literature was identified through the literature review in relation to mental health professionals' knowledge of ASD, with only two of the studies including mental health professionals as participants. Zerbo et al.'s (2015) sample included mental health providers (amongst other professionals) and Crane et al. (2019) solely explored ASD knowledge of Psychiatrists. Zerbo et al. (2015) found 70% of mental health providers rated their knowledge/skills in providing care to ASD patients as 'poor' or 'fair'. This study did not include a knowledge scale, but instead asked participants to self-rate their ASD knowledge; self-rating ASD knowledge rather than measuring ASD knowledge using a scale means the results can be considered

subjective. Alternatively, Crane et al. (2019) used a scale to measure ASD knowledge of Psychiatrists and found that psychiatrists achieved high scores on the scale (adjusted mean = 90.6%) suggesting high levels of ASD knowledge. The findings of the current study found mental health professionals do not have good knowledge of ASD, with good knowledge being considered a score of 80% on the scale. The qualitative Phase 1 findings suggested that participants considered professionals' knowledge of autism to be inadequate; participants also believed that the outcome of professional-service user interactions to be dependent on whether or not the service users believed that professionals had knowledge of autism. This suggests that professionals having a knowledge of autism can contribute to a better service user experience. The findings of Phase 1 and 2 taken together highlight a need for professionals' knowledge of ASD to be improved in order to better meet the needs of adults with autism accessing mental health services.

Further analyses indicated that there were statistically significant differences in the ASD knowledge scores obtained by the different professional groups in this study (Therapies, Social Care and Nursing). To the best of the researcher's knowledge, there has been no study yet undertaken that has compared the ASD knowledge held by differing mental health professions. In the current study, Therapies was found to have significantly higher ASD knowledge scores than both Social Care and Nursing; the same finding was true for ASD confidence. In addition, a moderately positive correlation was found between ASD knowledge scores and ASD confidence scores; this findings suggests that professionals with higher levels of ASD knowledge will have higher ASD confidence. This finding is consistent with the findings of Crane et al. (2019) who found higher self-efficacy scores to be significantly related to higher adjusted knowledge of autism scores indicating a relationship between professionals' ASD knowledge and their confidence in working with patients with autism. Additionally, in Maddox et al.'s (2019) both clinicians and agency leaders believed that limited knowledge of ASD resulted in low confidence as well as poor competence in working with people with autism. The findings of the current study confirm this, with lower ASD knowledge being associated with lower ASD confidence.

The current study also found ASD knowledge scores and ASD confidence scores to be significantly higher for professionals who had received ASD training compared to those who had not. This finding differs from the findings of Crane et al. (2019); in their

study, self-efficacy scores were higher for psychiatrists who had received ASD training (consistent with the findings of the current study), however, there was no significant difference in ASD knowledge scores between psychiatrists who had and had not received ASD training (not consistent with the findings of the current study). The findings of the current study suggest that ASD training can help to improve both ASD knowledge and ASD confidence of mental health professionals. It was contended by Maddox et al. (2019) that adults with autism should be involved in the creation and delivery of autism training to clinicians. The participants with autism in Maddox et al.'s (2019) study suggested recommendations for clinicians (which could be included in autism training) such as: a need to consider sensory issues, use clear and direct language, provide structure and predictability, be comfortable with silence and slow pacing, and a need to focus on treating the co-existing mental health conditions rather than trying to change traits associated with autism. Although the focus of the current study was to explore the ASD knowledge of mental health professionals, Clark et al. (2014) contended that administrative staff should also be offered autism training due to their role as being the frontline of the service. The importance of knowledge, confidence and training was also highlighted by Bradshaw et al. (2019) who contended that lacking ASD knowledge, confidence and training can result in barriers to accessing appropriate healthcare for individuals with autism.

8.4 Study Limitations

This study has explored the experiences of adults with autism accessing mental health services. This exploration has provided invaluable insight into the needs of this population, and whether or not their needs are currently being met by adult mental health services. Additionally, mental health professionals' ASD knowledge and confidence was measured which enabled hypotheses to be tested. However, this study does have its limitations.

8.4.1 Phase 1 Limitations

Due to the qualitative nature of Phase 1, in-depth understanding was prioritised over generalisability. In addition to this, the service user experiences that were captured in this study are specific to a particular health board located in Wales, and therefore the findings may not be generalisable to other health boards or places. Although, Barber (2017) stated that a one size fits all approach is not appropriate for individuals with

autism, he argued that many individuals with autism are likely to share similar healthcare issues, needs and expectations; this suggests that at least some of the findings of this study should be applicable in other settings. In relation to sample size, it could be contended that 20 participants for an IPA study is quite a large sample, as the focus should be on quality not quantity (Smith et al, 2009). However, Alase (2017) stated that an IPA study should include between 2 and 25 participants meaning that the sample size for the study is within the appropriate range. It is acknowledged by Smith et al. (2009) that the organisational constraints one is operating under can have an impact on the sample size; this was indeed the case in the current study as the health board wanted a range of participants to be involved in the study (whilst still ensuring the sample size was appropriate). Non-probability sampling was employed for Phase 1, specifically purposive, homogeneous sampling. This form of sampling allows participants to be purposefully selected as they all share a common experience from which understanding can be obtained (Gray, 2018). This form of sampling is not random and therefore no meaningful participation/response rate could be ascertained. The sample recruited were predominantly 'white' (90%); with 2 participants identifying as 'mixed race' (10%). According to the Welsh Government (2020), 94.8% of the population of Wales described their ethnic group as White. The remaining 5.2% of the population described themselves as 'Asian', 'Black', 'Mixed/multiple ethnic group' or 'other ethnic group' (Welsh Government, 2020). Although not all ethnicities were captured in the current study, the sample does include participants from ethnic minorities. An issue to consider in relation to autism prevalence and ethnicity is that the prevalence of autism in BME populations is lower compared to white populations, which can lead to further disadvantage of an already disadvantaged BME population and can impact upon the individual's wellbeing (John and Sala, 2018). In addition, the participants included in the current study were verbally and cognitive able (no participant reported having a co-existing LD); this could mean that the experiences captured in the current study do not reflect the experiences of individuals who are non-verbal or who have cognitive impairments. Also worth considering is that participants in the current study were recruited through approved recruiters in the health board; it could be argued that staff recruiting the participants could have opted to approach individuals that they knew had received positive experiences of services in order to portray the health board in a more positive way; it could be argued that an independent recruiter may have selected a different sample which could have led to very different

experiences. However, seeing as many of the participants in the current study shared at least some negative experiences, this may not be the case. This also suggests that individuals were not biased in sharing their experiences (e.g. bias such as social desirability and demand characteristics). Additionally, it must be considered that all participants in the current study had to self-select to take part, which in turn could mean that their experiences could vary from the views of participants who decided not to participate.

8.4.2 Phase 2 Limitations

Like Phase 1, Phase 2 also only included mental health professionals from one specific health board in Wales and therefore it may not be possible to extrapolate the findings from the current study to mental health services in alternative locations. Additionally, the number of participants who completed the questionnaire (N = 58) was low compared to the number of mental health professionals working in adult mental health services, which casts further doubt over the generalisability of the findings. The way in which the questionnaire was distributed could have contributed to the low numbers of participants obtained. Consistent with Phase 1, non-probability sampling was employed; however, this time a diverse purposive sample was obtained which allowed for a variety of mental health professionals to be recruited. The health board's Research and Development Team distributed the questionnaire, with the questionnaire being distributed to relevant team leaders who were then asked to disseminate the questionnaire onto their team members. The fact that the researcher was unable to distribute the questionnaire herself (also due to ethical approval) meant that the researcher was unable to send regular reminders or follow-up emails to all team leaders in an attempt to ensure that all mental health professionals actually received the questionnaire. It is highly likely that a substantial number of professionals within adult mental health services did not receive the questionnaire, and therefore could not complete it, which will have resulted in a lower number of participants and a potentially biased sample. Additionally, due to the way in which the questionnaire was distributed, no meaningful participation/response rate could be ascertained. Within the sample, several professions had few or only one participant as representation, for example, only one Psychiatrist, Psychologist and Mental Health Nursing Student took part meaning that differences between individual professions could not be investigated. In order to overcome this difficulty, the professions were categorised into

occupation categories (e.g. Nursing, Therapies and Social Care) in order to explore if any differences in knowledge and confidence were present according to occupation group. Furthermore, self-selection bias could also be present in Phase 2 of the current study, with individuals who have an interest in autism, or who are knowledgeable in autism, being more likely to participate. If this is the case, this could mean that the data obtained is biased, and does not correctly represent the target population. It could be argued that those who did not participate may in fact have lower levels of ASD knowledge and ASD confidence than those who participated, which could mean that the issue identified of lacking ASD knowledge and confidence in mental health professionals may actually be an under-estimate. Another limitation is that this study did not ask participants if they had a personal connection to autism, which may have impacted upon the findings as Crane et al. (2019) found there to be a link between having a personal connection to autism and ASD knowledge; this relationship was not found for ASD confidence. Although, in contrast to Crane et al. (2019), Knights et al. (2019) did not find previous experience or relationship with a person with autism to be a determinant of good ASD knowledge.

Despite the above mentioned limitations, the data collected from this study offers valuable insight into the experiences of adults with autism and co-existing mental health conditions of accessing adult mental health services. Additionally, the ASD knowledge of mental health professionals working across adult mental health services was measured and explored, which offers an original contribution to the literature.

8.5 Summary

Phase 1 of the current study involved the undertaking of qualitative analysis to explore the mental health service experiences of adults with autism. This exploration identified the following five superordinate themes: Experience of Autism Diagnosis, Staff Awareness of Autism, Facilitating Communication, Dissatisfaction, and Making Accommodations. These themes captured the participants' experiences of mental health services and assisted the identification of service needs for this population. Phase 2 of the study involved the undertaking of statistical analysis to explore ASD Knowledge and ASD Confidence of mental health professionals. The findings of this analysis indicated that mental health professionals do not have a 'good' knowledge of ASD. ASD Knowledge was found to positively correlate with ASD Confidence,

indicating a relationship between knowledge and confidence whereby higher knowledge is associated with higher confidence. ASD training was found to be associated with higher ASD Knowledge and ASD Confidence scores. This suggests a need to provide training to mental health professionals with the hope of improving professionals' knowledge and confidence in supporting adults with autism. Limitations in relation to both Phase 1 and Phase 2 of the current study were discussed.

The next chapter of this thesis conveys the key findings and conclusions of the current study specifically in relation to the research questions, and aims to make the contribution to knowledge explicit to the reader. Recommendations for both practice and for future research will be provided.

Chapter Nine: Conclusions and Recommendations

9.1 Introduction

This chapter begins by restating the aims of the current study before a summary of the key research findings are provided. The contribution to knowledge of this study will then be evidenced before a number of recommendations for practice and for future research are proposed. This will be followed by the researcher's post-data collection reflexive statement, before concluding remarks are provided.

9.2 Study aims

The study aims to be addressed in this study were:

1. To explore the needs and experiences of service users with co-existing autism and mental health disorder,

2. To establish whether the Health Board's adult mental health service met the needs of service users, and

3. To evaluate knowledge and understanding of ASD amongst staff working within adult mental health services in the Health Board.

The first two aims were addressed in Phase 1 (semi-structured interviews with service users) whilst the final aim was explored in Phase 2 (online questionnaire with mental health professionals). The key findings of the current study will be discussed below in order to address the study aims.

9.3 Key Research Findings

The current study identified a range of needs and experiences of adults with co-existing autism and mental health disorder in relation to their utilisation of adult mental health services. Participants shared their experiences of obtaining their autism diagnosis, their perceptions of staff's autism knowledge, their experiences of communicating with the health board, negative experiences which left them feeling dissatisfied, and highlighted areas where accommodations could be made. Numerous needs were highlighted within these themes.

In relation to their experiences of being diagnosed with autism, service users shared autism assessment processes that were inconsistent, and for some, the way the diagnosis was shared with them was ambiguous. Many participants conveyed a sense of enlightenment that was felt following diagnosis; however, many felt a strong need for post-diagnostic support, that for some was never received. For those who were diagnosed later in life, a negative effect was felt, which evidences a need for the early detection of autism.

The majority of participants spoke of a need for professionals to have an awareness and knowledge of autism, with many service users believing that a professional having knowledge of autism was a contributor to a positive service experience. Additionally, a need for professionals to see through the mask so that all individuals with autism are identified was evident, in order to ensure that service users can access the appropriate support.

A need for professionals to successfully communicate with this population was evident, as it was suggested that negative interactions could deter service users from seeking help in the future. Service users require information and updates to be shared in a clear way, that minimises ambiguity; it is suggested that minimising ambiguity could help to reduce service users' anxiety. Many participants portrayed a strong dislike for phone calls, and therefore there appears to be a need to contact this population by alternative methods, for example, by letter or email. As well as a need to ensure successful communication between the service and its service users, a need for better communication between and within services was also evident.

There were specific aspects to the service that service users were dissatisfied with; these include: the importance placed on medication rather than other types of support (for example, talking therapies), the current approach of mental health services being reactive to crisis rather than proactive in preventing them, long waiting times, service users' experiences of the Crisis Team and mental health inpatient settings, unclear pathways to accessing support, service users' falling through the cracks of current service provision, inconsistent processes for transferring service users from CAMHS to AMHS and a non-fulfilment of offered support. However, it is important to note that although the majority of participants shared experiences of the service that they were

dissatisfied with, many participants were grateful for the support they had received from mental health services, with several participants attributing their life to the service.

A need to make accommodations to support the current population to access mental health services was evident. Individuals with autism can experience sensory sensitivities which can make environments difficult to tolerate, and therefore a need for services to be aware of this and to make healthcare environments accessible was evident. Additionally, many participants felt there to be a need for consistency in relation to their care they receive from mental health services; for example, for their mental health professionals and appointments to be regular and consistent to aid with the development of rapport and continuity of their care. In relation to the support they access, a preference for one-to-one intervention was conveyed, however, several participants also discussed the benefit of attending an autism social group. The need to provide participants with choice in their mode of communication was also evident, with some participants wanting to communicate on occasion in writing. Additionally, a need for mental health professionals to act as an advocate for service users when necessary was present to ensure that their views are heard in a variety of settings.

On the basis of the current findings, it can be concluded that the needs of adults with autism and co-existing mental health disorder(s) are not being fully met in relation to the support they receive from adult mental health services; therefore, this means that there are areas of unmet need. The above discussion highlights particular aspects of the service that service users are dissatisfied with, and additional service needs were highlighted such as a need to: make the autism diagnostic process more consistent, facilitate communication, and to make accommodations which could contribute to improving the service user experience for this population.

In addition to the findings of Phase 1, Phase 2 explored the ASD knowledge and understanding held by mental health professionals working within adult mental health services. The findings indicated that mental health professionals do not possess a good level of ASD knowledge and understanding. A relationship between ASD knowledge and ASD confidence was present, whereby individuals with higher levels of ASD knowledge were more confident in their knowledge. Both ASD knowledge and ASD confidence was found to vary by occupation group, with professionals within the Therapies group having significantly higher ASD knowledge and ASD confidence than

professionals from Social Care and Nursing. Additionally, whether a professional had undertaken ASD training or not was found to impact upon ASD knowledge and ASD confidence, with ASD trained professionals having higher levels of ASD knowledge and ASD confidence. Based on the findings as a whole, it can be concluded that mental health professionals within adult mental health services do not possess a good level of ASD knowledge and could benefit from autism training, as the findings show ASD-trained professionals to have higher levels of ASD knowledge and ASD confidence. The Phase 2 findings correspond with the findings of Phase 1, whereby service users advocated a need for autism knowledge in adult mental health services, contending the current level of autism knowledge and understanding held by professionals to be inadequate. Additionally, service users believed that professionals having a knowledge of autism improved their service experience, with several participants specifically discussing training as a means to improving the autism knowledge of professionals.

9.4 Contribution to knowledge

The literature reviews contained within this thesis evidenced that there was very limited available evidence in relation to the aims of the current study. In relation to Phase 1, only three relevant articles were identified (Camm-Crosbie et al., 2018; Crane et al., 2018; Maddox et al., 2019), two of which were undertaken in the UK. The one study utilised an online questionnaire to obtain data, as where the other employed a mixed-method design to explore only the experiences of young adults with autism (aged 16-25) and only included participants from England. This would suggest that the undertaking of semi-structured interviews exploring the mental health service needs of adults with autism with co-existing mental health needs accessing services in Wales would be original contribution. Welsh healthcare is devolved and therefore Welsh service users could have a very different experience to those in other parts of the UK or further afield.

Another original contribution of this study was the exploration of ASD knowledge in a range of mental health professionals in a Welsh mental health service; the second literature review within this study identified only two studies exploring the ASD knowledge of mental health professionals. Within one study specific to the USA, mental health providers were included along with other healthcare professionals,

however it was not clear if these professionals worked within adult mental health services. Within the second study, only UK-based psychiatrists' ASD knowledge was explored. This suggests that the exploration of ASD knowledge in a variety of mental health professionals working within an adult mental health service within Wales would be an original contribution to current knowledge.

Additionally, the ASD knowledge questionnaire that was used within the current thesis was developed specifically for the purposes of this study (although based on existing measures) due to other tools not being appropriate to the current population (adults with autism and relevant to the UK); and therefore the questionnaire developed was an original contribution of the current study. This section has evidenced a number of ways in which the current study has contributed to the literature, however, whilst it is necessary to highlight the original contributions of the current thesis, it is important to acknowledge that any new knowledge obtained rests on the accumulation of previous and current literature (Dunleavy, 2003) as is the case with the current study.

9.5 Recommendations

The following recommendations are made based on the data obtained during the completion of the current study; the experiences and needs of service users with co-existing autism and mental health disorder as well as the level of ASD knowledge held by mental health practitioners has contributed to the following recommendations for both practice and future research.

9.5.1 Recommendations for practice

Below are recommendations for practice that arose from the analysis undertaken within the current study.

- A need for there to be a clear and consistent diagnostic process for individuals who are seeking an autism diagnosis, from the beginning of the process (from who to first approach) to the end (how the autism diagnosis is shared, and the post-diagnostic support given). The current study identified there to be large inconsistencies in each step of process for different service users; there may be a need to have different processes for individuals who are not currently accessing mental health services to those who are currently under primary or secondary mental health services.

- A need for autism training to help improve the knowledge and understanding of health board staff. Although this study only explored the autism knowledge of mental health professionals, it could be contended that all staff members who are patient-facing should undertake autism training, including administrative staff who are at the frontline of the service (Clark et al., 2014). NICE (2016) highlighted there to be different levels of knowledge required for varying members of staff within services. Therefore, it may be appropriate to offer a tiered approach to training, similar to the approach used in the 'Learning Disability Education Framework for Healthcare Staff in Wales' by Northway et al (2021). A tiered approach would mean that staff who specialise in providing support to adults with autism would be offered advanced autism training, with staff with lesser contact having a more foundational or enhanced level of training, dependent on their level of contact with adults with autism as part of their role. An anticipated barrier to implementing this recommendation would be the cost of creating/undertaking the training with staff members. Although there would be an upfront cost (staff time) to creating and implementing training, a way to minimise this cost would be to create an autism training module on ESR that staff can access and complete at their own convenience, rather than staff having to be allocated to face-to-face training days.
- In relation to communication, professionals should ask service users for their communication preferences. As highlighted in this study, individuals' needs can vary and therefore it is best to ask the service user what their communication preferences are. Also in relation to communication, there is a need for service users to remain informed throughout their care (for example, to be updated whilst on waiting lists, and to know what to expect during appointments in advance) in order to reduce uncertainty and therefore anxiety for the service user.
- Currently, according to the findings of this study, the mental health service provided to service users is crisis-driven; there appears to be a need for the service to become a system that works proactively to promote mental health and prevent mental health decline/crisis, rather than step in to offer support once the decline/crisis has already occurred. A way in which this could be implemented for people who are already known to mental health services, is for service users to have a designated contact to whom they can reach out to if

they feel that their mental health is deteriorating. Offering service users this point of contact could prevent a need for more costly and intensive acute support, as support/treatment could be offered at any earlier stage.

- The findings suggested a need for the Crisis Team to modify the support they currently provide to service users with autism and co-existing mental health disorders. The main purpose of Crisis Teams is to support those in crisis, and the findings of the current study indicated that service users did not feel that professionals from the Crisis Team were compassionate to their distress. The Care Quality Commission (2015) conveyed compassion to be a core part of starting an individual on the road to recovery, which supports the need for professionals with CRHT teams to convey compassion to their service users. However, this finding may not be specific only to the population being investigated as the Care Quality Commission (2015) found that 48% of their participants did not believe that CRHT teams had listened to their concerns, and that 43% felt that they were not treated with warmth and compassion. This suggests a need for Crisis Teams to listen to the service users' difficulties and to provide support in a compassionate way in order to improve service user experience.
- A need for healthcare environments to be autism friendly was evident in the findings of the current study. Specific areas of difficulty that were highlighted were lighting, temperature, acoustics and clocks. It is important to ensure that waiting rooms and consultation rooms are accessible to people with autism in order to ensure that adults with autism have equal access to healthcare to adults without autism; this argument is consistent with NICE (2016) guidance which highlights the importance of the physical environment in relation to individuals with autism, and contends a need to make adjustments/adaptions to the environment where necessary. An additional suggestion in relation to environments is to have a quiet waiting space that individuals with sensory sensitivities can utilise if they would like to; this could help to reduce any distress related to sensory sensitivities and could improve individuals' ability to successfully interact with professionals in appointments (Saqr et al., 2018). A barrier to making current facilities autism friendly is the associated cost. However, when new buildings are built, or current facilities refurbished, these could be designed in a way that shows an awareness and consideration of

sensory sensitivities; for example, fluorescent lighting could be avoided and waiting rooms could be laid out in a more patient-friendly way.

- The final recommendation for practice is a need for better collaboration between mental health services and the Integrated Autism Service (IAS). The IAS is a service whose staff are highly skilled in working with individuals with autism, whereas mental health services presumably would not have this level of knowledge. Additionally, due to the fact that approximately 4 in 5 individuals will have at least one co-existing mental health disorder during their lifetime (Lever and Geurts, 2016), the IAS by excluding adults with autism and co-existing mental health difficulties could potentially be excluding the majority of their target population. Due to the high prevalence of mental health difficulties in the current population, there appears to be a need for mental health services and IAS teams to work collaboratively to holistically support the needs of the current population.

9.5.2 Recommendations for research

The data collected within the current study has contributed to the existing knowledge in the following ways: (1) by exploring the service needs of adults with co-existing autism and mental health disorder, and (2) by establishing the ASD knowledge of professionals working within adult mental health services. However, there still remains a further need for research to be done in this area, with the ultimate goal being to improve mental health services and the quality of life for people on the spectrum (Maddox et al., 2020). Below are recommendations for future research:

- The current study could be replicated within other health boards in Wales to compare and contrast the experiences of service users, and to determine whether the service user experience is a shared one.
- The current study only included two participants from ethnic minorities and the current literature would benefit from further exploration of the experiences of service users from a range of backgrounds to explore whether individuals from ethnic minorities are disadvantaged in relation to mental health support, as is suggested by Crane et al. (2018).
- Using the questionnaire developed in the current study, a training intervention could be evaluated whereby participants are given the questionnaire pre- and

post-training to establish if the training delivered improved staff's levels of ASD knowledge and confidence.

- In contrast to the current study, service users' experiences of mental health services could be explored using quantitative means. For example, a questionnaire could be distributed which asked service users to evaluate individual elements of the service (for example, Outpatients, Inpatients, Crisis Team, Psychology, Occupational Therapy, etc.) using a rating scale. Using a quantitative tool may allow for a greater number of participants to participate as questionnaires are quicker to complete and can be done at service users' leisure. This proposed research would serve as a valuable comparison to the findings of the current study.
- In addition to obtaining the views of service users, it is also important to include other stakeholders such as staff; a potential suggestion for future research in relation to staff could be to explore staff's perceptions of delivering care to adults with autism within adult mental health services, and these findings could be compared with the findings of the current study to explore similarities and differences with service users' perspectives.

In addition to the specific recommendations above for further research, several areas were highlighted within the results of the current study that would benefit from further exploration. For example, further exploration could be undertaken in relation to what specific post-diagnostic support individuals with autism feel they would benefit from (or even the co-production of a post-diagnostic support pack), as well as investigating the transition from the CAMHS to AMHS or discharge, and the impact that has on the individual. Additionally, a study specifically exploring the experiences of adults with autism of accessing CRHTTs would be beneficial, in order to identify how this team can improve the care it delivers to this population.

The following section will contain the researcher's post-data collection reflexive statement, written in the first person, which will convey the researcher's journey of completing their PhD study.

9.6 Reflexive statement

In retrospect, my PhD studies feel like they have flown by. Looking back over the course of my studies, I feel grateful and privileged to have been given the opportunity

to meet some incredible people, both service users and staff members, and I have learnt so much during this time. In my first reflexive statement, I considered myself to have a reasonable understanding of what autism was, I now know that this was not the case. I may have read textbooks, and read the latest autism journal articles, but it was from listening to the experiences of my participant service users that I truly learnt about what living with autism is like, and even now I have much to learn. I cannot adequately convey how grateful I was, and still am, that twenty participants took the time to share their stories with me; I'll be forever grateful.

There were a few hurdles encountered along my PhD journey, one of which was obtaining ethical approval. On reflection, the most important skill in obtaining ethical approval was persistence, with ethical approval taking a total of 15 months to obtain. Although the process was lengthy and sometimes frustrating, I learnt a lot from it, including developing my ability to please numerous parties that sometimes conflict in terms of their views on an issue. One of the reasons that ethical approval took so long was due to the fact that the participants for Phase 1 (service users) were deemed 'high risk' and therefore the ethical review was more extensive. Whilst I completely understand the need to reduce harm and ensure the safety of any participant involved in research, I fear that having such a lengthy and extensive process in order to undertake research with this client group could deter researchers from engaging with this population, which could result in this population being deprived of the opportunity to take part in research. However, this may be reflective of a wider societal view that dealing with individuals with mental health conditions is 'risky'.

Once ethical approval was obtained, the next hurdle was recruitment. Ethical approval meant that I was unable to contact eligible service users myself, I instead had four approved recruiters who reached out to service users they knew to be eligible for the study to see if they were interested in taking part. It was only once I received the Permission to Contact Form that I was permitted to contact the service user to discuss the study. Whilst I acknowledge that this process was necessary to comply with the ethics committees, it was personally frustrating as I believe I could have recruited more participants to the study if I had been permitted to do follow-ups with eligible service users, for example, some service users' invite letter may have got lost in the post and therefore the service user may not have even been aware of the study taking place.

Once a service user had completed the Permission to Contact Form, I met with the service user once in-person to discuss the study, and complete documentation if the participant decided they wanted to participate, and a second time to undertake the research. I believe the fact that I had met the participant prior to their actual interview allowed them to meet me and hopefully come to be at ease with me, which would hopefully have lowered the anxiety they experienced prior to, and during the interview. Every interview was different, and it was only through the interviews that I truly grasped that once *"you've met one person with autism, you've met one person with autism"* (The Art of Autism, 2020). Through my PhD, I have started to question the usefulness of diagnoses; I acknowledge they are helpful as a way to provide service users access to services but I believe they can also be limiting as I don't believe individuals always sit nicely within clean-cut diagnostic boxes. There appears to be a need present to view and support individuals holistically, rather than trying to support co-existing diagnoses/difficulties in isolation. I felt this issue was present for the service users within this study; some participants reported that their care was targeting their co-existing conditions separately, and some reported feeling bounced around between services due to their co-existing diagnoses.

Undertaking the interviews with service users was by far my favourite part of my PhD project; I am still surprised by how open the participants were, and I'm grateful that they trusted me with their very personal experiences of living with autism and mental health, and of accessing services. Many of the participants shared past experiences that had been difficult for them, but several had also shared experiences where a certain professional had made a massive difference to their lives. Mental health services have the power to make such a difference to service users; I believe that two of the most valuable things professionals can do is listen to what the individual needs and act in a compassionate way. Many participants thanked me following the interviews, and I believe they felt valued due to someone taking the time to truly listen to them and their experience, at least I hope this to be the case.

Another difficulty I faced was in relation to choosing which quotes to include in my Phase 1 Results chapter, as so, so many quotes and experiences were captured in the interviews. Following the interviews, I felt a great sense of self-imposed pressure to ensure that I adequately communicated the findings of this study and did the participants' experiences justice. Undertaking this study has allowed me to truly

appreciate the benefit of using a mixed-method approach in research; I feel that using both the interviews and the online questionnaire in this study allowed for a broader picture of service provision to be understood, as service users' perceptions of professionals' ASD knowledge, and professionals' actual ASD knowledge scores could be contrasted. I enjoyed developing the questionnaire that was used to measure ASD knowledge in this study; existing ASD knowledge measures were not appropriate for the current study and therefore I created one based on several existing measures. This task allowed me to ensure that the questionnaire was appropriate for the study, and that the statements were based on up-to-date knowledge.

At the beginning of this project, I had a hope that undertaking this study would allow the health board to better understand the needs of service users with co-existing autism and mental health disorder, and for recommendations to be created which could lead to a better service experience for this population. I feel the recommendations within this thesis, if implemented, could make a difference to individuals with autism who access mental health services. For me, the Phase 2 findings clearly spoke of a need for training, but I also understand that any training needs to be compatible with the existing duties of staff, and therefore having the training available on ESR would allow staff members to access the training at their convenience. I hope that the research interest in obtaining the views of adults with autism and mental health disorder continues to grow, as I believe all services need to be guided by the needs of the population they serve. Services should not assume to know service users' needs, but should instead ask them, which is the case within the current study.

It appears on reflection, that I started my PhD studies knowing very little about what autism is, the mental health difficulties that are faced by many individuals with autism, and the current NHS provision for adults with co-existing autism and mental health disorder. I feel I have progressed a long way from where I started, but I equally acknowledge that I have so much more to learn. To conclude, my PhD journey has been a roller coaster, with both ups and downs, but I have no regrets and will forever remember this experience.

9.7 Concluding remarks

Prior to this study, there was very limited existing literature in relation to: (1) the needs and experiences of adults with co-existing autism and mental health disorder of accessing adult mental health services, and (2) the knowledge and understanding of ASD held by mental health professionals working in adult services. A need for health services research for adults with autism was contended by Murphy et al. (2016), who specifically stated that research was required to better understand the needs of this population and to obtain their views, which could in turn inform service development. Additionally, NICE (2019) states that individuals who access mental health services should be asked about their experiences, and that feedback obtained should be used to improve services.

This study has conveyed the service experiences of adults with co-existing autism and mental health disorder who have accessed mental health services, and has illustrated the needs of this population in relation to their accessing of mental health support. The findings of this study suggested that the mental health service is not currently meeting all of the service needs of adults with co-existing autism and mental health disorder, with participants highlighting areas of unmet need. Unmet support needs have been found to significantly predict suicidality for individuals with autism and therefore, there is a clear need for mental health services to address unmet support needs in this population in order to reduce the suicide risk of individuals with autism, who are already a high-risk group for dying by suicide (Cassidy et al., 2018).

In addition to exploring service users' needs and experiences, this study also evaluated the knowledge and understanding of ASD held by mental health professionals working within the adult mental health service. The findings suggested that mental health professionals have inadequate ASD knowledge. However, professionals who had attended ASD training had higher levels of ASD knowledge and ASD confidence suggesting that training may be a way to improve the ASD knowledge and ASD confidence of mental health professionals. Service users also highlighted the current level autism knowledge within adult mental health services to be inadequate, and proposed training as a way to address this. Improved autism knowledge in mental health services, as well as consideration of the recommendations for practice contained within this chapter, could help to improve the accessibility and

usability of mental health services for adults with autism. Although the current study has made a contribution to current literature, there remains further research ensuring the inclusion of participants with autism to be done, to ensure that services are delivered in a respectful, accessible and patient centred way to this population (Crane et al., 2019).

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Appendices

Appendix 1 – A selection of the researcher's reflective diary entries

Entry relevant to:	**Diary entry:**
Participant 1	"After thoroughly familiarising myself with the data, I felt ready to create exploratory comments. It was clear this participant had always perceived themselves as different; she struggles with dealing with, and expressing emotions and has at times felt alone. Receiving her diagnosis was life changing, in a very positive way. There is a sense of loss, over time where things could have been different if she'd known about her diagnosis sooner (frustration/disappointment)".
	"Looking back, I wish I had asked more follow-up questions. I was aware that I didn't want to lead her answers, but I feel I stuck too rigidly to the ethically approved questions. In future interviews, I will further explore issues that arise, even if they're unexpected".
Participant 7	"The process of reading and immersing myself into the transcript enlightened me to the difficulties the participant has experienced, and his frustrations. I felt empathetic to his experience. I found his comment about not being a stubborn teenager particularly interesting. Is this what he thinks others see him as? The concept of Alexithymia came through to me in this interview when he talks about his difficulties with

	emotions. Additionally, the need to be person-centred came through strongly throughout this transcript - this made me think to the NICE guidelines (CG142) for person-centred care in adults with ASD".
	"I found the process of exploratory commenting thought-provoking as its interpretative nature allowed me to explore what the participant was saying indirectly in the transcript. Condensing the exploratory comments and transcript into emergent themes was more challenging. I found that some of my themes were saying the same things with different words, and therefore I merged these. I found allocating a word to the themes difficult, it's hard to find a word or series of words that does a theme justice".
Participant 13	"Although not a specific question in the interview, this participant shared very personal experiences of self-harm and suicide attempts in the past with me. Within these experiences were areas for improvement within service provision. I admired the candour of this participant; she shared some very private and personal experiences highlighting how she felt dismissed and ignored. She found support to be unavailable to her. This participant felt no one cared about her until she'd tried to kill herself numerous times. She felt hopeless and despair, and no longer wanted to live. I felt honoured/humbled that she had shared this with me, but also sad that this was her experience. Reading this transcript again further drove my ambition to share the

	experiences of the participants of my study with the goal of improving mental health services".
	"A particular quote that stood out to me in this transcript was 'skills not pills'. This participant shared that she felt medication made her more likely to hurt herself; she believed medication to be a negative influence on her mental health. She rejected the idea of throwing medication at her difficulties, and instead wanted to support to develop her skills to cope/live with her condition(s). My thoughts on this is that medication should not be seen as a solution or the only option, however, medication may help some individuals. Service users' preferences for treatment/support should be taken into account by professionals when care planning. A need for professionals to listen to service users and their wishes seemed evident".
Participant 18	"I predicted this interview would feel different to the others due to the unusual route the participant had taken to be involved in the study. This participant was unaware of his autism diagnosis prior to bringing approached to take part in the study. I wondered how the participant would feel about the fact that his diagnosis had not been shared with him sooner: angry, frustrated, sad, confused? Whilst the participant contended that autism diagnoses should be shared in a clear, non-ambiguous way, he also shared that he was glad that he now knows about his diagnosis; he felt that it was an ideal time for him to find out. He was grateful to me and to the doctor who discussed the diagnosis with him (following our first meeting). My original predictions of his

	feelings were inaccurate; primarily, he was thankful. Yet again, the value of an autism diagnosis to an individual is evidenced".
	"Although I was disappointed that this participant was unaware of his rightful diagnosis, I was grateful that he participated in the study to highlight the importance of clear communication between professionals and service users (and their families)".
Bringing together the emergent themes for all transcripts	"The thought of bringing all the transcripts together was very exciting but also a bit overwhelming. There is a LOT of data, and I want to ensure that the analysis reflects the experiences of the participants who generously gave their time to the study. I lined up the themes that arose from each participant's transcript and I created a mind map. It was here that I brought all the participants experiences together. 'Communication' and 'diagnosis' were key topics, which were clearly going to form superordinate themes from the beginning. However, the superordinate theme surrounding accommodations took longer to finalise as I wanted theme titles which were accessible and clear. Themes around Autism knowledge were grouped together, and eventually it felt appropriate for masking to come within this superordinate theme. Bringing together the themes was a long but thoroughly enjoyable experience. On occasions, I had to have a time out and come back; seeing the themes with fresh eyes allowed me to move the themes around more easily. I was pleased with my final table of superordinate and subordinate themes; this was the culmination of years of hard work".

Writing the results chapter	"I really enjoyed writing this chapter. This chapter is a means of capturing and sharing the experiences of the participants in an accessible way for others to view. My main difficulty was deciding which quotes to include. There were SO MANY great quotations, and I originally felt a real need/urge to include them all. However, I was aware that this chapter was already going to be a long due to the number of themes, so my goal then became to ensure I included enough quotations to convey the idiographic focus of the study, without going overboard. I believe I achieved this balance."
My experience of IPA	"Whilst IPA is a very time-consuming and in-depth qualitative methodology/method, I am very glad that I chose this method. The phenomenological component ensured that the service users' experiences were central to the analysis, the hermeneutic element allowed me to convey service users' experiences in a way which specifically addressed the research question, and the idiographic focus ensured that individual participant's experiences did not get lost in the wider analysis. I believe I know a lot more about IPA following my PhD study than I did before, and I believe this method was a great choice for the current study. I acknowledge that having a sample size of 20 for IPA was on the larger side, and that this therefore made the process of analysis quite lengthy and more challenging; maybe in the future, a smaller sample size may be more appropriate".

Appendix 2 – Completed CASP Checklists by Category (Phase 1 Literature Review)

CATEGORY 1					
CASP QUALITATIVE CHECKLIST (Adapted)	Nicolaidis et al. (2013)	Barber (2017)	Tint and Weiss (2017)	Saqr et al. (2017)	Beresford et al. (2020)
1. Was there a clear statement of the aims of the research?	Yes	N/A**	Yes	Yes	Yes
2. Is the chosen methodology appropriate?	Yes	N/A**	Yes	Yes	Yes
Answering 'Y' to the two screening questions above is an indication to proceed with the remaining eight questions					
3. Was the research design appropriate to address the aims of the research?	Yes	N/A**	Yes	Yes	Yes
4. Was the recruitment strategy appropriate to the aims of the research?	Yes	N/A**	Yes	Yes	Yes
5. Was the data collected in a way that addressed the research issue?	Yes	N/A**	Yes	Yes	Yes
6. Has the relationship between researcher and participants been adequately considered?	N/A*	N/A**	Can't tell	Can't tell	Can't tell

7. Have ethical issues been taken into consideration?	Yes	N/A**	Yes	Can't tell	Yes
8. Was the data analyses sufficiently rigorous?	Yes	N/A**	Yes	Can't tell	Yes
9. Is there a clear statement of findings?	Yes	N/A**	Yes	Yes	Yes
10. How valuable is the research?	This study was the first study to directly obtain data from adults with autism about their perceptions of unmet needs, patient-provider communication and healthcare self-efficacy.	This article contended that healthcare service provision needed to be reviewed, with input from those on the spectrum. This paper included feedback from three adults with autism about their experiences with healthcare professionals.	This study was one of the first to offer insight into women's' experiences of accessing services, including health services. This paper found that women's' service needs tended to be misunderstood.	The findings of this study provide a better understanding of current health care access and delivery needs of both adolescents and adults with ASD.	Chapter 7 explored whether individuals' needs where met when accessing SATs, and investigated whether or not service characteristics and practices played a role in service user experience.

* This question has not been completed as the paper is a quantitative study.

** Barber (2017) was not fully critically appraised using the CASP Checklist as the study was not empirical.

CATEGORY 2			
CASP QUALITATIVE CHECKLIST (Adapted)	Nicolaidis et al. (2015)	**CASP SYSTEMATIC REVIEW CHECKLIST**	Bradshaw et al. (2019)
1. Was there a clear statement of the aims of the research?	Yes	1. Did the review address a clearly focused question?	Yes
2. Is the chosen methodology appropriate?	Yes	2. Did the authors look for the right type of papers?	Yes
Answering 'Y' to the two screening questions above is an indication to proceed with the remaining eight questions			
3. Was the research design appropriate to address the aims of the research?	Yes	3. Do you think all the important, relevant studies were included?	Can't tell
4. Was the recruitment strategy appropriate to the aims of the research?	Yes	4. Did the review's authors do enough to assess quality of the included studies?	Can't tell
5. Was the data collected in a way that addressed the research issue?	Yes	5. If the results of the review have been combined, was it reasonable to do so?	Yes
6. Has the relationship between researcher and participants been adequately considered?	Yes	6. What are the overall results of the review?	This review identified barriers and facilitators to healthcare for adults with autism without intellectual disability and grouped them into three categories: (1) patient-level factors, (2) provider-level factors, and (3) system-level factors.
7. Have ethical issues been taken into consideration?	Yes	7. How precise are the results?	N/A***

8. Was the data analyses sufficiently rigorous?	Yes	8. Can the results be applied to the local population?	Yes
9. Is there a clear statement of findings?	Yes	9. Were all the important outcomes considered?	Yes
10. How valuable is the research?	This study identified factors at the patient-level, provider-level and system-level that impacted upon healthcare experiences of adults on the autism spectrum. Additionally, this study communicated recommendations for improving care for this population.	10. Are the benefits worth the harms and costs?	Yes

*** This question is not applicable as the systematic review reports qualitative data.

CATEGORY 3			
CASP QUALITATIVE CHECKLIST (Adapted)	Dern and Sappok (2016)	Vogan et al. (2017)	Raymaker et al. (2017)
1. Was there a clear statement of the aims of the research?	Yes	Yes	Yes
2. Is the chosen methodology appropriate?	Yes	Yes	Yes
Answering 'Y' to the two screening questions above is an indication to proceed with the remaining eight questions			
3. Was the research design appropriate to address the aims of the research?	Yes	Yes	Yes
4. Was the recruitment strategy appropriate to the aims of the research?	Can't tell	Yes	Yes
5. Was the data collected in a way that addressed the research issue?	Can't tell	Yes	Yes
6. Has the relationship between researcher and participants been adequately considered?	Can't tell	N/A*	N/A*
7. Have ethical issues been taken into consideration?	No	Yes	Can't tell
8. Was the data analyses sufficiently rigorous?	Can't tell	Yes	Yes
9. Is there a clear statement of findings?	Yes	Yes	Yes

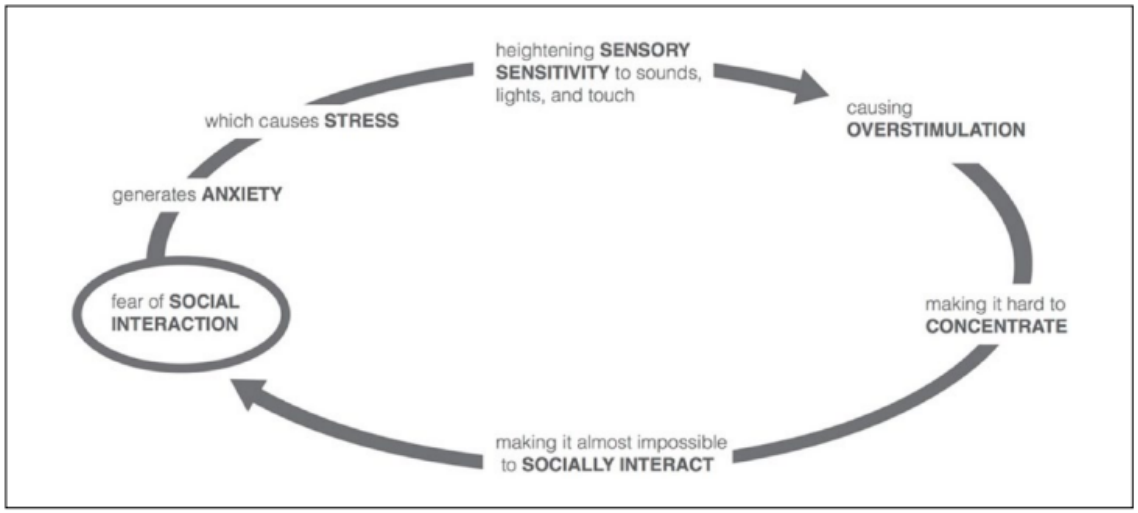
10. How valuable is the research?	This paper pooled the experiences of self-advocates with autism and the clinical experiences of practitioners to identify barriers to healthcare for adults with autism (of all intellectual abilities) and to also provide strategies to overcome these barriers.	This study was one of the first to track and explore current health care use patterns, satisfaction with services and barriers to service use from the perspective of adults with ASD without ID.	This study identified and compared barriers to healthcare between adults with autism, adults with other disabilities, and adults without disability. They developed a 'Barriers to Healthcare Checklist' to do this. They developed a long and short version of this form; the short version is more practical for use in clinical or research settings.

*
This question has not been completed as the paper is a quantitative study.

CATEGORY 4			
CASP QUALITATIVE CHECKLIST (Adapted)	Crane et al. (2018)	Camm-Crosbie et al. (2018)	Maddox et al. (2019)
1. Was there a clear statement of the aims of the research?	Yes	Yes	Yes
2. Is the chosen methodology appropriate?	Yes	Yes	Yes
Answering 'Y' to the two screening questions above is an indication to proceed with the remaining eight questions			
3. Was the research design appropriate to address the aims of the research?	Yes	Yes	Yes
4. Was the recruitment strategy appropriate to the aims of the research?	Yes	Yes	Yes
5. Was the data collected in a way that addressed the research issue?	Yes	Yes	Yes
6. Has the relationship between researcher and participants been adequately considered?	Yes	Yes	Yes
7. Have ethical issues been taken into consideration?	Yes	Yes	Yes
8. Was the data analyses sufficiently rigorous?	Yes	Yes	Yes
9. Is there a clear statement of findings?	Yes	Yes	Yes

10. How valuable is the research?	This study obtained the views and experiences of young adults with autism and co-existing mental health problems, and explored how this population can be best supported.	This study was one of the first to explore the experiences of adults with autism in relation to treatment and support for mental health problems and suicidality.	This study was one of the first to explore ways to address the mental health needs of adults with autism within community mental health centres. This study included adults with autism, community mental health clinicians and community mental health agency leaders.

Appendix 3 – Visual depiction of negative feedback loop which results in difficulties in social interaction for individuals with autism.



Appendix 4 – Filters applied to search terms for all databases (Phase 2 Literature Review)

Search Term(s)	Database and filters applied
knowledge OR experience OR understanding OR awareness	Science Direct: Title, abstract or author-specified keywords CINAHL: Abstract MEDLINE: Abstract ProQuest Psychology: Abstract ProQuest Nursing & Allied Health: Abstract PsychInfo: Abstract ASSIA: Abstract PubMed: Title/Abstract
autism OR autism spectrum disorder	Science Direct: Title, abstract or author-specified keywords CINAHL: Abstract MEDLINE: Abstract ProQuest Psychology: Abstract ProQuest Nursing & Allied Health: Abstract PsychInfo: Abstract ASSIA: Abstract PubMed: Title/Abstract
survey OR questionnaire OR instrument OR measure OR assessment OR scale	Science Direct: Title, abstract or author-specified keywords CINAHL: Abstract MEDLINE: Abstract ProQuest Psychology: Abstract ProQuest Nursing & Allied Health: Abstract PsychInfo: Abstract ASSIA: Abstract PubMed: Title/Abstract
professional OR staff OR therapist OR practitioner	Science Direct: N/A CINAHL: N/A MEDLINE: N/A ProQuest Psychology: N/A ProQuest Nursing & Allied Health: N/A PsychInfo: N/A ASSIA: N/A PubMed: All Fields
healthcare OR mental health	Science Direct: N/A CINAHL: N/A MEDLINE: N/A ProQuest Psychology: N/A ProQuest Nursing & Allied Health: N/A PsychInfo: N/A ASSIA: N/A PubMed: All Fields

adult	Science Direct: N/A CINAHL: N/A MEDLINE: N/A ProQuest Psychology: N/A ProQuest Nursing & Allied Health: N/A PsychInfo: N/A ASSIA: N/A PubMed: All Fields
NOT (child OR children)	Science Direct: Title, abstract or author-specified keywords CINAHL: Title MEDLINE: Title ProQuest Psychology: Document title ProQuest Nursing & Allied Health: Document title PsychInfo: Document title ASSIA: Document title PubMed: Title

Appendix 5 – Completed CASP Checklists (Phase 2 Literature Review)

PHASE 2 LITERATURE REVIEW						
CASP QUALITATIVE CHECKLIST (Adapted)	Clark et al. (2014)	Zerbo et al. (2015)	Unigwe et al. (2017)	Crane et al. (2019)	Knights et al. (2019)	van't Hof et al. (2020)
1. Was there a clear statement of the aims of the research?	Yes	Yes	Yes	Yes	Yes	Yes
2. Is the chosen methodology appropriate?	Yes	Yes	Yes	Yes	Yes	Yes
Answering 'Y' to the two screening questions above is an indication to proceed with the remaining eight questions						
3. Was the research design appropriate to address the aims of the research?	Yes	Yes	Yes	Yes	Yes	Yes
4. Was the recruitment strategy appropriate to the aims of the research?	Can't tell	Yes	Yes	Yes	Yes	Yes
5. Was the data collected in a way that addressed the research issue?	Yes	Yes	Yes	Yes	Yes	Yes
6. Has the relationship between researcher and participants been adequately considered?	Can't tell	Can't tell	N/A*	N/A*	N/A*	N/A*

7. Have ethical issues been taken into consideration?	Yes	Yes	Yes	Yes	Yes	Yes
8. Was the data analysis sufficiently rigorous?	Can't tell	Yes	Yes	Yes	Yes	Yes
9. Is there a clear statement of findings?	Yes	Yes	Yes	Yes	Yes	Yes
10. How valuable is the research?	This study used an online questionnaire to evaluate levels of autism knowledge in both clinical and administrative staff from community Learning Disability teams. Administrative staff then received autism training and took part in a follow-up focus group to provide feedback on the autism training session they had received.	This study was the first study to use a quantitative survey and subsequent qualitative interviews to explore healthcare providers' knowledge and attitudes of autism in adults.	This was the first study to use a reasonably large sample of GPs from the UK to explore their perspectives on working with patients with ASD.	This study was the first to focus exclusively on psychiatrists' knowledge, experience and confidence in working with their patients with autism.	This study was the first in Australia to measure community pharmacists' knowledge of ASD and the appropriateness and accessibility of pharmacies for people with ASD.	This study measured both the ASD knowledge and stigmatising attitudes towards mental illness of 93 physicians at Dutch Youth and Family Centres (YFC). This study highlighted that ASD knowledge and stigmatising attitudes in physicians in YFC require attention.

* This question has not been completed as the paper is a quantitative/predominantly quantitative.

Appendix 6 – Participant Information Sheet (Service Users)

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PARTICIPANT INFORMATION SHEET – SERVICE USERS

Study Title

Exploring the needs of service users with a co-existing mental health and neurodevelopmental disorder accessing Mental Health Services in [redacted]

Invitation paragraph

I would like to invite you to take part in a research study. Before you decide, you need to understand why the research is being done and what it involves. Please take time to read the following information carefully before you decide whether or not to take part. Ask questions if anything you read is not clear or if you would like more information.

What is the purpose of the study?

The purpose of the study is to evaluate [redacted] Mental Health Service from the perspective of individuals who have co-existing mental health disorder and Autism Spectrum Disorder (ASD). The aim is to establish the needs of service users who are currently accessing the Mental Health Service in [redacted] and determine whether these identified needs are being met. This study is being undertaken as part of a PhD qualification.

Why have I been invited?

Individuals who take part in this study would have been referred by a member of their direct clinical care team at [redacted] as they fulfil the inclusion criteria for taking part in this study. The inclusion criteria is that participants must be aged between 18 and 65, be from within the West Wales and Valleys region, have co-occurring mental health disorder and ASD and must be currently accessing the Mental Health Service within [redacted] in either primary or secondary care.

Do I have to take part?

No, you do not have to take part. It is your choice whether you want to participate in the study. After reading this information sheet you should understand the purpose of the study and what is involved, and then you can make an informed decision as to whether or not you want to take part. If you decide to take part, you will be asked to sign a consent form to demonstrate that you consent to participate in the study. You have the right to withdraw from the study at any time, and this will not affect the standard of care you receive.

What will happen to me if I take part?

If you decide to take part, you are consenting to completing a demographic form and taking part in a focus group. You will be given a choice as to whether they want to participate in an online or face-to-face focus group. The online focus group will involve the use of a programme called Blackboard Collaborate and can be completed in the comfort of your own home; alternatively, the face-to-face focus groups will be undertaken at a [redacted]site. Blackboard Collaborate is an online platform that will be used to facilitate the online focus groups in this project. Blackboard Collaborate will allow participants to type their responses to focus group questions, instead of having to verbalise their answers. Once the online focus group has finished, the transcript will be saved by the researcher and identifiable information will be removed.

The focus groups will be organised at a date and time convenient for you. Focus groups will last approximately one hour and you will be sent the focus group questions to consider before taking part in the focus group. By agreeing to take part in this study, you are also consenting to [redacted] sharing your neurodevelopmental and mental health diagnoses with the research team. For individuals who decide to take part in a face-to-face focus group, the session will be audio-recorded and later transcribed. For those who take part online, the transcripts will be saved to Microsoft Word. Conversation generated in the focus groups will be qualitatively analysed but individual responses will be anonymised, meaning your identity will not be known in any reports or publications. If you would feel more comfortable participating in an individual interview (either online or face-to-face) rather than a focus group, please let the researcher (Chelsea Courts) know who will be able to arrange this.

What will I have to do?
You will be expected to participate in either an online or face-to-face focus group/individual interview which involves answering questions about what you feel your needs as a service user are, and whether you feel these needs are being met by the Mental Health Service or Primary Care Service within [redacted] It is your choice whether you want to take part in an online or face-to-face focus group.

What are the possible disadvantages and risks of taking part?
The focus groups questions were developed to evaluate Mental Health Services in [redacted] and therefore, are not meant to be of an upsetting nature. However, there is a possibility that focus group discussion could evoke upsetting feelings if difficult memories are raised. Support will be available for both modes of focus group (online or face-to-face). For online focus groups, you will be issued with a contact number of a mental health practitioner independent of the study who can offer advice. For face-to-face focus groups, there will be a break-away room in which you can go to if you feel overwhelmed. In this room there will be a mental health practitioner independent of the project who can provide support if necessary.

What are the possible benefits of taking part?
Discussion generated in the focus group will help to inform the way in which the Mental Health Service in [redacted] is run and delivered to service users. The answers participants give during the focus groups will help develop suggested improvements which could be made to the services that participants are accessing in [redacted] This project is a two-phased study; the first phase involves service users (you) and the second phase involves Mental Health Practitioners within [redacted] In the second phase, Mental Health Practitioners will complete a questionnaire to assess knowledge and understanding of Autism Spectrum Disorder, and then there will be a follow-up focus group. Concerns/issues which are raised by service users in the service user focus groups will be discussed by staff and these findings will be fed back to [redacted] to help improve services.

What if there is a problem?
If you have a concern about any aspect of this study, you should contact a member of the research team who will do their best to address that concern.

Research Student:
Chelsea Erica Courts (chelsea.courts@southwales.ac.uk)
Research Supervisors:
Anne Fothergill (anne.fothergill@southwales.ac.uk)
Catherine Purcell (catherine.purcell@southwales.ac.uk)

Ruth Northway (ruth.northway@southwales.ac.uk)
[redacted] Clinical Advisor:
Emma Francis (emma.francis@wales.nhs.uk)

If you feel your concern hasn't been addressed by the above contacts, and wish to complain formally, you can do this through contacting Jonathan Sinfield at the University of South Wales (jonathan.sinfield@southwales.ac.uk / 01443484518) or contacting the Cwm Taf Morgannwg University Health Board's Concerns team on 01443 744800.

Will my taking part in the study be kept confidential?
The University of South Wales is the sponsor for this study based in Wales. We will be using information from you in order to undertake this study and will act as the data controller for this study. This means that we are responsible for looking after your information and using it properly. The University of South Wales will keep information about you for 10 years from the first day of data collection. Data will be stored on password-protected computers (accessible only by the research team) with hard copies being stored in a lockable cabinet in a lockable room. After the 10 years has passed, all electronic data will be deleted, and paper-based data will be shredded and disposed of in confidential waste. Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally-identifiable information possible.

Chelsea Courts will keep your name and contact details confidential and will not pass this information to the University of South Wales. A Permission to Contact Form will be given to you to complete in order for your contact details to be passed onto the researcher in order to contact you. Chelsea Courts will use your information as needed, to contact you about the research study, and make sure that relevant information about the study is recorded for your care, and to oversee the quality of the study. Members of the research team and regulatory organisations may look at your research data to check the accuracy of the research study. In order to try and maintain confidentiality within the focus groups, participants will be asked at the beginning of the focus groups to keep what they hear confidential. However, unfortunately, the researcher and research team cannot guarantee that comments made within the focus group will not be shared by other participants although this will be strongly discouraged by the researcher. The only scenario in which confidentiality will be breached by the researcher is if illegal activity, misconduct, or harm (potential or actual) is disclosed to them. The University of South Wales will only receive information without any identifying information. The people who analyse the information will not be able to identify you and will not be able to find out your name or contact details. Chelsea Courts will not keep any identifiable information about you from this study once the study has finished.

What will happen if I don't carry on with the study?
If you decide to withdraw from the study, all data collected up to your withdrawal will still be used. No identifiable data will be used in this study.

What will happen to the results of the research study?
The results of the study will form a PhD thesis which has the potential to be published in the future. A poster will be created once all focus groups and analysis has been completed to illustrate the findings from the focus groups, and this will be sent to you on completion. Answers given in the focus groups will be anonymised and no individual responses will be identifiable from the study. The results of the study, including direct anonymised quotes

from the focus groups/interviews, will be published/presented in journal articles, study specific reports and at conferences.

Who is organising or sponsoring the research?
The University of South Wales is the sponsor of the research, with supporting funding from KESS 2 and [redacted]. This research project is covered by University of South Wales insurance and indemnity arrangements.

Who has reviewed the study?
This study has been reviewed and given favourable opinion by the Wales Research Ethics Committee 1. This study has also been reviewed internally by the University of South Wales, and externally by the University of Bangor. The Life Sciences and Education Faculty Ethics Committee (University of South Wales) has ethically approved this study.

Further information and contact details:

Contact Details

Research Student:
Chelsea Erica Courts (chelsea.courts@southwales.ac.uk)
Research Supervisors:
Anne Fothergill (anne.fothergill@southwales.ac.uk)
Catherine Purcell (catherine.purcell@southwales.ac.uk)
Ruth Northway (ruth.northway@southwales.ac.uk)
Research Governance Officer:
Jonathan Sinfield (jonathan.sinfield@southwales.ac.uk)

Further Information

Mental Health Foundation:
https://www.mentalhealth.org.uk/

Mind:
https://www.mind.org.uk/

Hafal:
http://www.hafal.org/

The National Autistic Society:
http://www.autism.org.uk

ASD Info Wales:
http://www.asdinfowales.co.uk/home/

Autistica:
https://www.autistica.org.uk/

Appendix 7 – Permission to Contact Form

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PERMISSION TO CONTACT FORM

I would like to inform you about a project that is being undertaken at [redacted] entitled *'Exploring the needs of service users with a co-existing mental health and neurodevelopmental disorder accessing Mental Health Services in* [redacted]
The project is being undertaken by Chelsea Courts, a PhD Student at the University of South Wales.

The project will involve taking part in a focus group (or individual interview if preferred) either face-to-face or online. The purpose of the focus group is to explore the needs of service users with co-existing Autism Spectrum Disorder and mental health disorder, and to establish whether [redacted] are meeting these identified needs. The focus group will take approximately 1 hour.

If you are interested in taking part, you will be contacted in order to provide you with more information. If you are happy for your contact details to be passed on in order to be contacted about participating in the project, please provide your contact details, name and signature on the following page.

Yours Sincerely,
Chelsea Courts

Version number: 3
Date: 09.09.2019 IRAS 237661

Please provide your preferred contact details below:

Home Address: _____

_____

_____

_____

_____

Home Number: _____

Mobile Number: _____

Email Address: _____

Name of Potential Participant: _____

Signature: _____ **Date:** _____

The below is for research purposes; you do not need to complete this.

Name of Person taking Consent: _____

Signature: _____ **Date:** _____

Appendix 8 – Template Invitation Letter




Invitation to take part in a study

I would like to inform you about a research study that is being undertaken in [redacted] entitled `*Exploring the needs of service users with a co-existing mental health and neurodevelopmental disorder accessing Mental Health Services in* [redacted] The study is being carried out by Chelsea Courts, a PhD Student at the University of South Wales.

The study will involve the undertaking of a focus group or individual interview, either online or face-to-face.

I have enclosed a copy of the information sheet for you to read but if you need any further information or would like to talk to someone before you decide whether or not to take part, you can ring Chelsea Courts on .....(number to be confirmed).

If you decide you would like to take part, or would like more information, please complete the enclosed Permission to Contact Form and send this back to Chelsea Courts using the enclosed pre-paid envelope. This will allow the research student to contact you to discuss the study.

Please be aware that you are under no obligation to take part in this study.

Yours sincerely,

..... (Signature)

..... (Name in print)

Version number: 2
Date: 09/09/2019 IRAS 237661

Appendix 9 – Recruitment Poster for GP Practices

Do you have co-existing Mental Health Disorder and Autism Spectrum Disorder?

Are you aged between 18 and 65?

Are you currently accessing Mental Health Services in [redacted]

If the above questions apply to you, there is research being undertaken that you may be interested in taking part in.

Study title: Exploring the needs of service users with a co-existing mental health and neurodevelopmental disorder accessing Mental Health Services in [redacted]

Your participation would involve attending a focus group (or individual interview if preferred) either online or face-to-face. The focus group will take approximately one hour and will explore your needs as service users, and whether these needs are being met by the Health Board. This research is being undertaken by Chelsea Courts, a PhD Student at the University of South Wales.

For more information about taking part, please contact Chelsea on chelsea.courts@southwales.ac.uk or 07748 032471

Version number: 3
Date: 09/09/2019 IRAS 237661

Appendix 10 – Interview Questions (Service Users)

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FOCUS GROUP QUESTIONS – SERVICE USERS

Please be aware that although the researcher will take every precaution to maintain confidentiality of the data, the nature of focus groups means that the researcher cannot guarantee confidentiality. The researcher would like to encourage participants to respect the privacy of their co-participants by not repeating what is said in the focus group to others.

1. What led you to accessing the Mental Health Service?
2. What do you feel you need from the Mental Health Service?
3. Do you feel you have been adequately supported by the Mental Health Service, and how so?
4. Explain whether or not you feel that Mental Health Practitioners fully understand all your needs?
5. What do you like about the Mental Health Service you access?
6. What do you dislike about the Mental Health Service you access?
7. Explain whether or not you feel your needs, which were discussed earlier in the focus group, are being met by the Mental Health Service?
8. Is there anything else you would like to discuss that has not already been raised in this focus group?
9. Describe your experience of being diagnosed with Autism Spectrum Disorder (ASD).
10. Describe your experience of accessing the Mental Health Service.
11. Describe the services you are currently accessing within [redacted]
12. Describe the support/interventions you are currently receiving within [redacted]
13. How has accessing the Mental Health Service influenced your quality of life?
14. Describe your experience with staff within the Mental Health Service.
15. Which method/s of communication would you prefer? (e.g. telephone, letter, email, text)
16. Do you feel the waiting times for an appointment with the Mental Health Service are satisfactory? Explain your answer.

Prioritised questions

Questions to be asked if time allows

Appendix 11 – Consent Form (Service Users)

USW - FACULTY OF LIFE SCIENCES AND EDUCATION

STUDY CONSENT FORM – SERVICE USERS

Title of Project: Exploring the needs of service users with a co-existing mental health and neurodevelopmental disorder accessing Mental Health Services in [redacted]

Name of Research Student: Chelsea Erica Courts

Name of Academic Supervisors: Dr. Anne Fothergill, Dr. Catherine Purcell and Prof. Ruth Northway

Please initial all boxes

1. I confirm that I have read and understand the information sheet dated 09.09.2019 (version 5) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐
2. I agree to my neurodevelopmental disorder and mental health diagnoses being shared with the research team by [redacted] ☐
3. I agree to be contacted by Chelsea Courts to arrange a suitable date and time to take part in the focus groups. ☐
4. I acknowledge that if I disclose any sensitive information to the research student (e.g. regarding criminal activity, or possible harm to myself or others) that the research student will have to share that information to relevant parties/authorities. ☐
5. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason and without any consequence to myself. I understand that my participation will not affect the care/services I access in [redacted] ☐
6. I agree to the focus group being audio-recorded (for face-to-face focus groups) or the focus group transcript being saved (for the online focus groups) for analysis. ☐
7. I agree to my anonymised data being used in a PhD thesis, study specific reports, academic journal articles and conference presentations. ☐
8. I agree to statements I make within the individual interview/focus group being used as anonymised quotes within a PhD thesis, journal articles, study specific reports and at conference presentations. ☐
9. I agree to take part in the above study. ☐

Please tick two boxes below (one from each row) to show your preferred method of participation:

☐ Online ☐ Face-to-face

☐ Focus group ☐ Individual interview

P.T.O

Version number: 5
Date: 09/09/2019 IRAS 237661

Name of Participant	Date	Signature
Name of person taking consent	Date	Signature

Appendix 12 – Demographic Form (Service Users)

USW - FACULTY OF LIFE SCIENCES AND EDUCATION


DEMOGRAPHIC FORM – SERVICE USERS

Title of Project: Exploring the needs of service users with a co-existing mental health and neurodevelopmental disorder accessing Mental Health Services in [redacted]

Please complete all questions and tick the boxes that apply to you.

Participant Number:_____

Age: _____

Sex: ☐ Female ☐ Male ☐ Other ☐ Prefer not to say

Ethnicity:

☐	White
☐	Asian
☐	Black/African
☐	Hispanic/Latino
☐	Mixed Race
☐	Other

Marital Status:

☐	Single
☐	Cohabiting
☐	Married
☐	Separated
☐	Divorced
☐	Widowed
☐	Other

Are you employed? ☐ Yes ☐ No

If yes, please tick below all employment types that apply to you:

☐ Full-time ☐ Part-time ☐ Casual ☐ Paid ☐ Voluntary

☐ Unpaid (e.g. internships) ☐ Apprenticeship ☐ Self-employed

☐ Other

If other, please specify: _____

At what age were you diagnosed with Autism Spectrum Disorder (ASD)? _____

In what year were you diagnosed with ASD? _____

Where were you diagnosed with ASD? (e.g. location, in what service?)

_____

Do you have any other Neurodevelopmental Disorders as well as ASD?

☐	Dyslexia	☐	Dyspraxia
☐	ADHD	☐	Speech and Language Impairment
☐	Dyscalculia	☐	Learning Disability
☐	Other		

If other, please specify: _____

Did you receive any mental health disorder diagnoses before being diagnosed with Autism Spectrum Disorder? If so, name them.

_____

What are your current mental health diagnoses?

_____

Who referred you to your current Mental Health Service?

_____

Appendix 13 – Debrief Form (Service Users)

USW - FACULTY OF LIFE SCIENCES AND EDUCATION

STUDY DEBRIEF FORM – SERVICE USERS

Research Title: Exploring the needs of service users with a co-existing mental health and neurodevelopmental disorder accessing Mental Health Services in [redacted]

Thank you for taking part in this study. The aim of this study was firstly to establish the needs of service users with co-occurring neurodevelopmental and mental health disorder, and secondly to determine whether these needs are being met by [redacted] This was done through the use of focus groups and individual interviews (either online or face-to-face). This study was part of a two phased research project. The first phase involved service users, and the second phase involved Mental Health Practitioners completing an ASD Knowledge Questionnaire and taking part in a follow-up focus group. The results from this study will be used to try and improve the services delivered to individuals with co-existing mental health and Autism Spectrum Disorder by [redacted]

Any data obtained through this research will be held confidentially and will only be seen by the research team. No data will be identifiable in this project.

If after participating in this study you have a concern you would like to discuss, you can contact a member of the research team who will do their best to address that concern.

Chelsea Erica Courts (chelsea.courts@southwales.ac.uk)
Anne Fothergill (anne.fothergill@southwales.ac.uk)
Catherine Purcell (purcellc2@cardiff.ac.uk)
Ruth Northway (ruth.northway@southwales.ac.uk)
Emma Francis (emma.francis@wales.nhs.uk)

If you feel your concern has not been adequately addressed by the above contacts, please contact Jonathan Sinfield (Research Governance Officer) at the University of South Wales (jonathan.sinfield@southwales.ac.uk or 01443484518).

For further information, please see the below websites:

Mental Health Foundation:
https://www.mentalhealth.org.uk/

Mind:
https://www.mind.org.uk/

Hafal:
http://www.hafal.org/

The National Autistic Society:
http://www.autism.org.uk

ASD Info Wales:
http://www.asdinfowales.co.uk/home/

Autistica:
https://www.autistica.org.uk/

Version number: 4
Date: 09/09/2019 IRAS 237661

Appendix 14 – Confirmation of Capacity Form




CONFIRMATION OF CAPACITY FORM

Project Title: Exploring the needs of service users with a co-existing mental health and neurodevelopmental disorder accessing Mental Health Services in [redacted]

Participant Name: _____

In the context of this study, being assessed as having capacity means that the participant must be able to:

- Understand the information relevant to making the decision as to whether or not they want to take part in the study
- Retain the information long enough to make the decision
- Use the information to assist their decision making
- Communicate their decision to the researcher in some way

I confirm that the above named participant was assessed as having capacity and was therefore able to give their consent to take part in this study.

Name of Researcher: _____

Signature: _____ **Date:** _____

Version number: 2
Date: 09/09/2019 IRAS 237661

Appendix 15 – Tables illustrating the development of subordinate and superordinate themes from participant quotes (for Participant 6 and Participant 10)

Participant 6

Quote(s)	Subordinate Theme	Superordinate Theme
"It was a continuous fight even then to see someone who would eventually refer me to the correct person, who could then diagnose me in a single session of less than one hour"	Assessment process	Experience of autism diagnosis
"At the time they gave me I think three options eh... or I could have all of them if I wanted and I chose all of them … they said there's a group in Pontypridd that meets, it's an ASD group so everyone in the group other than the people running it are on the spectrum and it's a social group and I thought that's a bit weird because you know after reading up everything … social group for ASD that seems a bit odd but … that was a thing and then, um, mindfulness which is again is at the Maritime they said that might … be something we can offer so they offered that and also access to *PROFESSIONAL* who still works with me today"	Post-diagnostic support	
"Had I been diagnosed much, much earlier and it was recognised earlier, maybe that would be different"	Negative impact of late diagnosis	
"Yeah it's polar, it's very polar, they either know a lot or they know nothing", "For people in the mental health business um you know, there's an	Need for knowledge	Staff awareness of autism

expectation that they would know what it is at the very least", "Mental Health Practitioners are not equal in their approach or understanding of ASD. Some have read medical journals and studies into ASD in children and try to apply their book-learned knowledge in the wider field. My experience on the receiving end of such advice is that they have poor understanding and many of the beliefs they hold are simply untrue. Some people try to treat the symptoms, without realising there is an underlying cause. Others have more experience face-to-face with us and are open-minded enough to form their own opinions and admit there is a lot to learn", "There are so many points of failure. Right from the get-go, getting a diagnosis is difficult and frustrating, with GPs lacking in training or specialist knowledge and without a clue who to refer one to", "Training is so important um you know there needs to be more understanding and education when it comes to dealing with people with autism", "The education isn't there they're not … being educated in what it is and what it needs", "I had to explain the meaning of the word 'spectrum' to them, as they assumed everyone to have an equal need", "The training is not universal so it all depends on who you talk to um you walk into the GP's office you've no idea whether the person you're talking too has even heard of autism or whether they're just nodding and smiling and you know", "Then we need some method of initial access to diagnosis and training for any and all staff critical to assisting us"		

“Mine [My GP] refused to deal with my questions pertaining to Autism, preferring to treat depression and depressive symptoms, which they had at least heard of. Unfortunately, their medication route took many months of trial and error, made my life extremely difficult and ended up putting me in hospital”,	Impact of knowledge / understanding	
“masking is one of the … biggest problem, I guess, that we have is that we spend most of our energy masking the problem so that we can fit in so that we can communicate, um, and then the energy that we're left with is not enough to cope”, “Somebody who identified um the problem despite the mask … They saw through that and was just like well yeah you know we can ask the right questions, we can have the right conversation and we can see that that's how it works”, “Yeah so to have somebody who just bypassed that and was completely open to it who understood, it was … unique … I think that's the only person that I've spoken to with that level of understanding uh and yes I was lucky to find somebody who was that well trained”	Masking	

“It's easier to talk on the phone when it's not personally me … That I'm talking about, I find that incredibly stressful uh I get very anxious talking to people on the phone if I don't know who they are and that I'm giving them you know personal information uh I tend to avoid it if at all possible and would prefer I prefer email … um that's my that's my go to because with an email you can put your thoughts on the page and if you don't like what you've written if you think well that's you know maybe that could misinterpreted maybe that's, that's not what I'm trying to say or maybe there's something I haven't said … often on the phone I'll, I'll become anxious and then I won't say what I want to say and then after I put the phone down I'll think I should have said this I should have said that why didn't I say these things and you know email gives you the opportunity to you know to check it”	Method of contact	Facilitating communication
“But there's … no clear pathway to well, you know, we'll signpost you to the right place”, “When you think you're autistic, you go to your GP, that seems to be the logical place and there's … no- one else that you can really go to, so you go there, and they don't know, they can't diagnose you, so then you've gotta be signposted back and forth until somebody goes oh yeah I know who you need to talk to … and it seems to be a handful of people who actually deal with it, there's very few people, but … you know those that are, are very highly trained and they can deal with it, it's the rest of the world that can't”, “If there was some, um I don't know, some regulation that said somebody walks	Unclear pathways	Dissatisfaction

through the door who claims to be autistic then these are the procedures, and this is how we deal with that, um then I think that would be a … distinct improvement over walking in and having to explain your condition … To someone who can't necessarily point you in the right direction", "Consistency is kind of important to us, we do need to have that kind of regular this is what you do so if you have a problem you know who to talk to"		
"Dealing with us in the first place is difficult for the mental health board because they don't know how to categorise us on one hand we're mental health but do we have a mental illness no it's not really an illness that's just how we are we're born that way so you know it's not a mental illness is it a learning disability well clearly not some of us can learn it depends on whether we're being taught so it's not really a learning disability it's how do you classify it. It's not medical so we get passed off it's not mental health because we can't, we don't have any facilities for that so we'll pass you off to medical but medical's looking at it, there's nothing physically wrong with you know you're fine so we can't treat you with medications we can't help you in in any way that we understand so they bring us back to the mental health service because it's … not their responsibility, we just kinda get passed back and forth until somebody sits up and goes yes actually I do know what this is and maybe we can help"	Falling through the cracks	

“I honestly believe that without her frequent and decisive interventions during some intensely difficult times, I would not be here today”	Gratitude	
“The group at first because again you know, it wasn't something I'd really thought about before and suddenly I was on the spectrum, so I'm learning all of this about it and being around people who are also on the spectrum taught me a lot about how we are, and who we are, … and also I, … the unusual thing is that the group was, it was a social group and it worked as a social group, you know people got along just fine which contradicted what I'd read about, what I'd researched, ... that contradicted all that information, um... and everybody in the group seemed to do … well”	Support preferences	Making accommodations
“But I myself need an advocate, I need somebody who can speak on my behalf, you know that's something we all need”	Advocacy	

Participant 10

Quote(s)	Subordinate Theme	Superordinate Theme
“Cause I feel I've been misunderstood for years”, “Yeah I think the earlier people are diagnosed the better but obviously at the moment there's a lot of adults who haven't been diagnosed”	Negative impact of late diagnosis	Experience of autism diagnosis
“I think more, definitely more awareness, … so like where I've got autism, where I like say I struggle with like eye contact or I struggle with groups it's misinterpreted as like not engaging and it’s not that I'm not engaging if I didn't want help I wouldn't be there would I, but you know it's often misinterpreted I suppose”, “I think more awareness across like all services but the fact that some people haven't got a diagnosis of autism but they could still be struggling with it”	Need for knowledge	Staff awareness of autism
“If they know like the certain signs like they got a patient who really struggles with eye contact uh you know maybe doesn't like the lights on or something you know would be a good idea if they could have like maybe warning signs … So they could say maybe this persons on the spectrum and just do one of those like an autism questionnaire and then see if it's worth looking into further”	Impact of knowledge	

“Cause bearing in mind autistic people have worked quite hard usually at masking conforming to social expectations to avoid their issues … And it's not an instinct that's lost easily”	Masking	
“Phone … I bet everyone says that don't they like I can do the phone but I don't like it at all … knowing when it's like your turn to speak or you know sometimes I come across like I'm interrupting people but what it's like its … But what usually happens is like they're talking about something and they stop to think and I think they've finished talking … And then I start asking questions or saying something and it’s don't interrupt me oops sorry didn't mean it”, “They ring off withheld numbers which I don't answer, I never answer withheld”	Method of contact	Facilitating communication
“No, autistic people like to know what, a little bit about what's going on and have a rough idea, and you know when I was like sort of in limbo and I didn't know what was going on and that kind of didn't help with the … anxiety, lack of organisation and you know it, it didn't help”, “They don't keep me informed of what's going on so they could at least write a letter saying just say oh I've uh you know you've got x amount of months to wait you know but you are on the waiting list and maybe just send us an update here and there saying like oh you've moved up the waiting list now and you've only got this amount to wait you know just keep us informed I think would be a would be a good idea”	Minimising ambiguity	

“I think the problem is perhaps lack of awareness, so maybe a bit more communication between like primary and secondary care or … at least with the … people who work with autistic people as well, maybe primary care could communicate more with them … You know to see like what can we do to help this autistic person who struggles with you know sensory issues what would you suggest or you know that kind of thing”	Disconnect between / within departments	
“That's a hell of a long time to wait and things shouldn't have to escalate to be able to get help should they … You know once you start struggling, you should be able to have, just get in and sort it out … ‘Cause like you wouldn't have to wait until the cancers nearly killed you to get treatment because they want you to get treated earlier, mental health should be treated in the same way”	Reactive not proactive	Dissatisfaction
“Yeah exactly, ‘cause like you say when you're waiting six months things can change quite, quite a lot can't they?”, “But there's always things … like waiting lists, they are ridiculous, … there seems to be a lack of organisation sometimes as well… you know like somebody'll go off sick and then I don't hear from them for months and I don't know what's happening, and you know sometimes I've had to go back to my GP ‘cause I think I've been discharged and I haven't”	Waiting times	
“I've seen crisis teams and I've been forced to A&E but they're not very helpful so I usually refuse them”	Acute services	

“The option for lights or no ticking clocks you know that kind of stuff”, “Maybe even if it is practical like have a, a quieter waiting space you know, I wish hospitals would do that as well you know, have like a, a sort of side quieter … area like … You know where there's no screaming kids or people talking and … you get the picture”	Environment	Making accommodations
“Yeah and if the workers were more consistent as well, ‘cause I feel like I've seen you know so many different workers you know, which … that doesn't exactly help”, “Yeah I mean it’s like people wouldn't go up to a complete stranger would they and just start talking about all their personal stuff would they? … Nobody would, so that, that would be helpful if we had consistency with the workers instead of just getting passed around”, “Where I've had like you know an assessment and then waited six months, have to go in for another assessment, and then another six months, at least that was done over in like two weeks”	Need for consistency	
“Like I said more one to one stuff as well … ‘cause autistic people don't do groups very well”, “The problem is with groups I often have to take somebody with me cause when I get overwhelmed I can't really explain it very well and I just kind of end up running off … and the thing is then though, I can't be as open if I've got somebody with me ‘cause there's certain things I can't talk about so … what I'm finding is the emphasis seems to be on groups and there’s not so much one to one stuff available”, “Maybe the ability to like	Support preferences	

contact … like mental health people with like via email or something like before the sessions so then they can get like a chance perhaps to read through it and know what questions to ask rather than us having to like babble on and get nervous and freeze up and …start talking about other things”		

Appendix 16 – Participant Information Sheet (Staff)

USW - FACULTY OF LIFE SCIENCES AND EDUCATION

PARTICIPANT INFORMATION SHEET – STAFF

Study Title

Exploring the needs of service users with a co-existing mental health and neurodevelopmental disorder accessing Mental Health Services in [redacted]

Invitation paragraph

We would like to invite you to take part in a research study. Before you decide you need to understand why the research is being done and what it involves. Please take time to read the following information carefully before you decide whether or not to take part. Ask questions if anything you read is not clear or if would like more information.

What is the purpose of the study?

This study is being undertaken as part of a PhD qualification. This project is a two-phased study involving both service users and staff. In this study, service users will have co-occurring Autism Spectrum Disorder (ASD) and mental health disorder and staff will include Mental Health Practitioners.

The **first phase** involves service users taking part in focus groups to establish service users' needs, and to determine whether or not these needs are being met by Mental Health Services at [redacted]

The **second phase**, involving Mental Health Practitioners, is to assess staff knowledge and understanding of Autism Spectrum Disorder (ASD) using a questionnaire.

Why have I been invited?

Mental Health Practitioners working for [redacted] within the Adult Mental Health Service will be invited take part in the study. Mental Health Practitioners from both inpatient and community mental health teams will be invited to participate. Mental Health Practitioners can include, but are not limited to, nurses, occupational therapists, psychologists, psychiatrists, social workers and health care support workers.

Do I have to take part?

No, you do not have to take part. It is your choice whether you want to participate in the study. After reading this information sheet you should understand the purpose of the study and what participation entails, and then you can make an informed decision as to whether or not you want to take part. You have the right to withdraw from the study at any time.

What will happen to me if I take part?

Participants will be asked to complete a questionnaire and will then be given the opportunity to take part in a follow-up focus group. The questionnaire will be accessible through the [redacted] Intranet. The questionnaire consists of 28 questions (part a and b). Part a questions are true and false questions, and part b questions have three possible answers: not at all confident, confident and very confident. Following completion of the questionnaire, there will be the option for you to enter your email address independently of the questionnaire, to indicate that you would be interested in taking part in an optional follow-up focus group. The focus group will explore staff perceptions of their knowledge and understanding of ASD in relation to feedback given by service users in Phase 1 of the

study. The estimated duration of the follow-up focus group is one hour and it will be held at a NHS venue in [redacted] If you decide to complete the questionnaire, there is no requirement for you to take part in the focus group. If you decide to take part in the follow-up focus group, you will need to sign a consent form. The focus group will be audio-recorded and the recording transcribed for qualitative analysis. Individual responses will be anonymised.

What are the possible disadvantages and risks of taking part?
One perceived disadvantage of taking part in this study would be taking approximately 5 minutes of your time to complete the questionnaire and an additional 60 minutes if you choose to take part in the optional follow-up focus group. The questionnaire and focus group are aimed to investigate staff perceptions of their knowledge and understanding of Autism Spectrum Disorder. Therefore, none of the questions are known/intended to be of an upsetting nature. However, if you feel you need to speak to someone after taking part in the study, please contact a member of the Research Team or your line manager. Alternatively, if you have queries regarding your Continuing Professional Development (CPD) or your own practice, and do not wish to speak to your line manager, a list of professional bodies and their corresponding websites are listed at the bottom of this document. For those who decide to take part in the follow-up focus group, another possible disadvantage is that you could be identified by something you say in the focus group. When the focus group recording is transcribed, names will be removed and all statements will be anonymous. However, the researcher cannot guarantee that other individuals in the focus group will not share comments you have made in the focus group. It may also be possible that you could be identified purely by the things you say in the focus group. Therefore you must consider that there is a small chance comments made in the focus group will be identifiable.

What are the possible benefits of taking part?
Questionnaire responses given and discussion generated in the focus group will help to inform the way in which the Mental Health Service in [redacted] is run and delivered to service users with co-occurring ASD and mental health disorder. The answers given by participants will help develop suggested improvements to the service delivery model.

What if there is a problem?
If you have a concern about any aspect of this study, you should contact a member of the research team who will do their best to address that concern.

Research Student:
Chelsea Erica Courts (chelsea.courts@southwales.ac.uk)
Research Supervisors:
Anne Fothergill (anne.fothergill@southwales.ac.uk)
Catherine Purcell (catherine.purcell@southwales.ac.uk)
Ruth Northway (ruth.northway@southwales.ac.uk)
CTMUHB Clinical Advisor:
Emma Francis (emma.francis@wales.nhs.uk)

If you feel your concern hasn't been addressed by the above contacts, and wish to complain formally, you can do this through contacting Jonathan Sinfield at the University of South Wales (jonathan.sinfield@southwales.ac.uk or 01443484518).

Will my taking part in the study be kept confidential?
The University of South Wales is the sponsor for this study based in Wales. We will be using information from you in order to undertake this study and will act as the data controller for this study. This means that we are responsible for looking after your information and using it properly. The University of South Wales will keep information about you for 10 years from the first day of data collection. Data will be stored on password-protected computers (accessible only by the research team) with hard copies being stored in a lockable cabinet in a lockable room. After the 10 years has passed, all electronic data will be deleted, and paper-based data will be shredded and disposed of in confidential waste. Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally-identifiable information possible.

Chelsea Courts will keep your name and contact details confidential and will not pass this information to the University of South Wales. Chelsea Courts will use this information as needed, to contact you about the research study and to oversee the quality of the study. Members of the research team and regulatory organisations may look at your research data to check the accuracy of the research study. In order to try and maintain confidentiality within the focus groups, participants will be asked at the beginning of the focus groups to keep what they hear confidential. However, unfortunately, the researcher and research team cannot guarantee that comments made within the focus group will not be shared by other participants although this will be strongly discouraged by the researcher. The only scenario in which confidentiality will be breached is if illegal activity, misconduct, or harm (potential or actual) is disclosed to the researcher. The University of South Wales will only receive information without any identifying information. The people who analyse the information will not be able to identify you and will not be able to find out your name or contact details. Chelsea Courts will not keep any identifiable information about you from this study once the study has finished.

What will happen if I don't carry on with the study?
If you decide to withdraw from the study, all data collected up to your withdrawal will still be used. No identifiable data will be used in this study.

What will happen to the results of the research study?
The results of the study will form a PhD thesis which has the potential to be published in the future. Questionnaire and focus group responses will be anonymised. The results of the study, including direct anonymised quotes from the follow-up focus group, will be published/presented in journal articles, study specific reports and at conferences.

Who is organising or sponsoring the research?
The University of South Wales is the sponsor of the research, with supporting funding from KESS 2 and [redacted]. This research project is covered by University of South Wales insurance and indemnity arrangements.

Who has reviewed the study?
This study has been reviewed and given favourable opinion by the Wales Research Ethics Committee 1. This study has also been reviewed internally by the University of South Wales, and externally by the University of Bangor. The Life Sciences and Education Faculty Ethics Committee (University of South Wales) has ethically approved this study.

Further information and contact details:

Contact Details:

Research Student:
Chelsea Erica Courts (chelsea.courts@southwales.ac.uk)
Research Supervisors:
Anne Fothergill (anne.fothergill@southwales.ac.uk)
Catherine Purcell (catherine.purcell@southwales.ac.uk)
Joyce Kenkre (joyce.kenkre@southwales.ac.uk)
Research Governance Officer:
Jonathan Sinfield (jonathan.sinfield@southwales.ac.uk)

Further Information:

Mental Health Foundation:
https://www.mentalhealth.org.uk/

National Autistic Society:
http://www.autism.org.uk/

ASD Info Wales:
http://www.asdinfowales.co.uk/home/

FutureLearn:
https://www.futurelearn.com/courses/autism

Relevant Professional Bodies:

General Medical Council (GMC)
https://www.gmc-uk.org/

Nursing and Midwifery Council
https://www.nmc.org.uk

Social Care Wales (SCW)
https://socialcare.wales

Health and Care Professions Council (HCPC)
http://www.hcpc-uk.org/

Appendix 17 – ASD Staff Questionnaire

USW - FACULTY OF LIFE SCIENCES AND EDUCATION

Knowledge and Understanding of Autism Spectrum Disorder (ASD)

The below questionnaire intends to establish your knowledge and understanding of Autism Spectrum Disorder (ASD). The questionnaire is anonymous. Before undertaking the questionnaire, please indicate your occupation below by ticking the correct box, and providing your year of qualification.

Participant Occupation: (please tick)

Psychologist		Nurse	
Psychiatrist		Physiotherapist	
Occupational Therapist		Support Worker	
Social Worker		Other (please specify below)	
Student (please specify below)			

If other/student, please specify: _____

Year of qualification: _____

Have you been offered training on Autism Spectrum Disorder?

Yes / No (delete as appropriate)

Have you undertaken training on Autism Spectrum Disorder?

Yes / No (delete as appropriate)

If you have undertaken Autism Spectrum Disorder training,

- who was the training provider? _____
- when was the training undertaken? _____

This questionnaire consists of 28 questions (part a and b). Part a questions are a statement about Autism Spectrum Disorder to which you need to answer TRUE, FALSE or REALLY DON'T KNOW. Please only answer REALLY DON'T KNOW if you have no idea of the answer; if you have a feeling you might know the answer, please instead answer TRUE or FALSE. Part b questions require you to rate your confidence in the answer you provided to the statement in part a as either: NOT AT ALL CONFIDENT, CONFIDENT or VERY CONFIDENT.

Please consider each of the statements below and indicate your answer.

1a. Adults can never be diagnosed with ASD.

True	False	Really Don't Know

1b. Rate your confidence in the answer you provided to the above question.

Not at all Confident	Confident	Very Confident

2a. There is currently no medical test to diagnose ASD.

True	False	Really Don't Know

2b. Rate your confidence in the answer you provided to the above question.

Not at all Confident	Confident	Very Confident

3a. ASD is more frequently diagnosed in males than in females.

True	False	Really Don't Know

3b. Rate your confidence in the answer you provided to the above question.

Not at all Confident	Confident	Very Confident

4a. ASD tends to run in families.

True	False	Really Don't Know

4b. Rate your confidence in the answer you provided to the above question.

Not at all Confident	Confident	Very Confident

5a. There is no single recognised treatment for ASD.

True	False	Really Don't Know

5b. Rate your confidence in the answer you provided to the above question.

Not at all Confident	Confident	Very Confident

6a. The biggest problem with diagnosing ASD is that symptoms do not appear until age five or older.

True	False	Really Don't Know

6b. Rate your confidence in the answer you provided to the above question.

Not at all Confident	Confident	Very Confident

7a. An individual can be diagnosed with both ASD and Learning Disability.

True	False	Really Don't Know

7b. Rate your confidence in the answer you provided to the above question.

Not at all Confident	Confident	Very Confident

8a. ASD is a brain disorder.

True	False	Really Don't Know

8b. Rate your confidence in the answer you provided to the above question.

Not at all Confident	Confident	Very Confident

9a. There is currently no cure for ASD.

True	False	Really Don't Know

9b. Rate your confidence in the answer you provided to the above question.

Not at all Confident	Confident	Very Confident

10a. Most evidence suggests that ASD can be caused by vaccines.

True	False	Really Don't Know

10b. Rate your confidence in the answer you provided to the above question.

Not at all Confident	Confident	Very Confident

11a. Many individuals with ASD have trouble sleeping.

True	False	Really Don't Know

11b. Rate your confidence in the answer you provided to the above question.

Not at all Confident	Confident	Very Confident

12a. One common treatment for ASD is Dialectical Behaviour Therapy.

True	False	Really Don't Know

12b. Rate your confidence in the answer you provided to the above question.

Not at all Confident	Confident	Very Confident

13a. Individuals with ASD have difficulty interacting socially.

True	False	Really Don't Know

13b. Rate your confidence in the answer you provided to the above question.

Not at all Confident	Confident	Very Confident

14a. After being diagnosed, the presentation of ASD remains stable throughout the individual's life.

True	False	Really Don't Know

14b. Rate your confidence in the answer you provided to the above question.

Not at all Confident	Confident	Very Confident

15a. Problems during birth (e.g. foetal distress, breech presentation) have been linked to ASD.

True	False	Really Don't Know

15b. Rate your confidence in the answer you provided to the above question.

Not at all Confident	Confident	Very Confident

16a. Many scientists believe that ASD is a product of abnormal brain development.

True	False	Really Don't Know

16b. Rate your confidence in the answer you provided to the above question.

Not at all Confident	Confident	Very Confident

17a. A larger proportion of individuals with ASD remain non-verbal throughout their lives, compared to the general population.

True	False	Really Don't Know

17b. Rate your confidence in the answer you provided to the above question.

Not at all Confident	Confident	Very Confident

18a. The prevalence of ASD has increased over the past 10 years.

True	False	Really Don't Know

18b. Rate your confidence in the answer you provided to the above question.

Not at all Confident	Confident	Very Confident

19a. All people with ASD are extremely impaired and cannot live independently as adults.

True	False	Really Don't Know

19b. Rate your confidence in the answer you provided to the above question.

Not at all Confident	Confident	Very Confident

20a. There is a wide range of severity among individuals with ASD.

True	False	Really Don't Know

20b. Rate your confidence in the answer you provided to the above question.

Not at all Confident	Confident	Very Confident

21a. Most scientists and doctors know what causes ASD.

True	False	Really Don't Know

21b. Rate your confidence in the answer you provided to the above question.

Not at all Confident	Confident	Very Confident

22a. The diagnosis of ASD varies by race/ethnicity.

True	False	Really Don't Know

22b. Rate your confidence in the answer you provided to the above question.

Not at all Confident	Confident	Very Confident

23a. Individuals with ASD often engage in restrictive, repetitive behaviours.

True	False	Really Don't Know

23b. Rate your confidence in the answer you provided to the above question.

Not at all Confident	Confident	Very Confident

24a. Individuals with ASD cannot show affection.

True	False	Really Don't Know

24b. Rate your confidence in the answer you provided to the above question.

Not at all Confident	Confident	Very Confident

25a. There is a specific gene that can be used to identify ASD.

True	False	Really Don't Know

25b. Rate your confidence in the answer you provided to the above question.

Not at all Confident	Confident	Very Confident

26a. Some individuals with ASD have trouble tolerating loud noises or certain types of touch.

True	False	Really Don't Know

26b. Rate your confidence in the answer you provided to the above question.

Not at all Confident	Confident	Very Confident

27a. Individuals with ASD rarely form intimate relationships, even with their parents.

True	False	Really Don't Know

27b. Rate your confidence in the answer you provided to the above question.

Not at all Confident	Confident	Very Confident

28a. Because of their lower social awareness, individuals with ASD rarely have anxiety disorders.

True	False	Really Don't Know

28b. Rate your confidence in the answer you provided to the above question.

Not at all Confident	Confident	Very Confident

If after completing the above questionnaire you would be interested in taking part in a follow-up focus group exploring staff perceptions of Autism Spectrum Disorder in relation to feedback from service users in Phase 1 of the study, please follow the link below:

https://www.surveymonkey.co.uk/r/PCHYKQZ

This link will take you to a page where you can enter your email address to express an interest in taking part. Indicating an interest to take part in the focus group does not mean you are obliged to take part. A Participant Information Sheet and Consent Form will be sent to the email address you provide. You can then decide if you would still like to take part.

STUDY DEBRIEF FORM – STAFF

Research Title: Exploring the needs of service users with a co-existing mental health and neurodevelopmental disorder accessing Mental Health Services in [redacted]

Thank you for taking part in this study. This study had two phases; the first involving service users and the second involving practitioners. The first phase aimed to establish the needs of service users with co-occurring Autism Spectrum Disorder and mental health disorder, and secondly to determine whether these needs were being met by [redacted] This was done through the use of focus groups and individual interviews (either online or face-to-face). The second phase involved practitioners completing an ASD Knowledge Questionnaire, and then optionally taking part in a follow-up focus group. The aim of the focus group will be to investigate staff perceptions of their knowledge and understanding of ASD in relation to feedback given by service users in Phase 1. The results from this study will be used to try and improve the services delivered to individuals with co-existing mental ill-health and ASD by [redacted]

Any data obtained through this research will be held confidentially and will only be seen by the research team. All data will be anonymised.

If after participating in this study you have a concern you would like to discuss, you can contact a member of the research team who will do their best to address that concern.

Chelsea Erica Courts (chelsea.courts@southwales.ac.uk)
Anne Fothergill (anne.fothergill@southwales.ac.uk)
Catherine Purcell (purcellc2@cardiff.ac.uk)
Ruth Northway (ruth.northway@southwales.ac.uk)
Emma Francis (emma.francis@wales.nhs.uk)

If you feel your concern has not been adequately addressed by the above contacts, please contact Jonathan Sinfield (Research Governance Officer) at the University of South Wales (jonathan.sinfield@southwales.ac.uk or 01443484518).

For further information about ASD, please see the below websites:

Mental Health Foundation:
https://www.mentalhealth.org.uk/

National Autistic Society:
http://www.autism.org.uk

ASD Info Wales:
http://www.asdinfowales.co.uk/home/

FutureLearn:
https://www.futurelearn.com/courses/autism

Relevant Professional Bodies:

General Medical Council (GMC)
https://www.gmc-uk.org/

Nursing and Midwifery Council
https://www.nmc.org.uk

Social Care Wales (SCW)
https://socialcare.wales

Health and Care Professions Council (HCPC)
http://www.hcpc-uk.org/

Appendix 18 – ASD Questionnaire Answer Sheet

Statement Number	Statement	Answer
1	Adults can never be diagnosed with ASD.	FALSE
2	There is currently no medical test to diagnose ASD.	TRUE
3	ASD is more frequently diagnosed in males than in females.	TRUE
4	ASD tends to run in families.	TRUE
5	There is no single recognised treatment for ASD.	TRUE
6	The biggest problem with diagnosing ASD is that symptoms do not appear until age five or older.	FALSE
7	An individual can be diagnosed with both ASD and Learning Disability.	TRUE
8	ASD is a brain disorder.	TRUE
9	There is currently no cure for ASD.	TRUE
10	Most evidence suggests that ASD can be caused by vaccines.	FALSE
11	Many individuals with ASD have trouble sleeping.	TRUE
12	One common treatment for ASD is Dialectical Behaviour Therapy.	TRUE
13	Individuals with ASD have difficulty interacting socially.	TRUE
14	After being diagnosed, the presentation of ASD remains stable throughout the individual's life.	FALSE
15	Problems during birth (e.g. foetal distress, breech presentation) have been linked to ASD.	TRUE
16	Many scientists believe that ASD is a product of abnormal brain development.	TRUE
17	A larger proportion of individuals with ASD remain non-verbal throughout their lives, compared to the general population.	TRUE
18	The prevalence of ASD has increased over the past 10 years.	TRUE
19	All people with ASD are extremely impaired and cannot live independently as adults.	FALSE
20	There is a wide range of severity among individuals with ASD.	TRUE
21	Most scientists and doctors know what causes ASD.	FALSE
22	The diagnosis of ASD varies by race/ethnicity.	TRUE
23	Individuals with ASD often engage in restrictive, repetitive behaviours.	TRUE
24	Individuals with ASD cannot show affection.	FALSE
25	There is a specific gene that can be used to identify ASD.	FALSE
26	Some individuals with ASD have trouble tolerating loud noises or certain types of touch.	TRUE

27	Individuals with ASD rarely form intimate relationships, even with their parents.	FALSE
28	Because of their lower social awareness, individuals with ASD rarely have anxiety disorders.	FALSE

Appendix 19 – USW Ethical Approval Letter

University of South Wales
Prifysgol De Cymru

Professor Julie E Lydon OBE, Vice-Chancellor
Yr Athro Julie E Lydon OBE, Is-Ganghellor

19th September 2018

Ms Chelsea Courts
C/o Faculty of Life Sciences and Education
University of South Wales

Dear Chelsea,

Faculty Ethics Sub Group Feedback – 'Exploring the needs of service users with a co-existing mental health and neurodevelopmental disorder accessing Mental Health Services in [redacted] [18CC0201]

I am writing to confirm that on the 19/9/2018, the Faculty of Life Sciences and Education Ethics Sub Group approved your submission for ethical approval.

Please note:

i. Approval is valid for 2 years from the date of issue, you will be notified when approval has expired but you are expected to be mindful of this expiration. Upon the expiration of this ethics approval you may apply for an extension.

ii. The approved documents are attached. If you intend on deviating from the approved protocol, research team, or documentation you will need to seek approval for any changes.

iii. This approval does not confirm that indemnity or insurance are in place for this project.

iv. Please confirm when your research project has closed (a one page closure report highlighting any recruitment issues, adverse events, publications etc. should be appended).

If you have any queries about the committee's decision, please do not hesitate to contact me.

Yours sincerely,

Professor Peter McCarthy
Chair of Faculty Ethics Committee

Appendix 20 – Wales Research Ethics Committee Approval Letter

Ymchwil Iechyd a Gofal Cymru
Health and Care Research Wales

Gwasanaeth Moeseg Ymchwil
Research Ethics Service

Ariennir gan Lywodraeth Cymru
Funded by Welsh Government

Wales Research Ethics Committee 1
Castlebridge 4
15-19 Cowbridge Road East
Cardiff
CF11 9AB

Telephone: 02920 785738
E-mail: jagit.sidhu@wales.nhs.uk
Website : www.hra.nhs.uk

Please note: This is the favourable opinion of the REC only and does not allow you to start your study at NHS sites in England until you receive HRA Approval

25 March 2019

Miss Chelsea E Courts
University of South Wales
Cemetery Road
Glyntaff, Pontypridd
CF37 4BD

Dear Miss Courts

Study title:	**Exploring the needs of service users with a co-existing mental health and neurodevelopmental disorder accessing Mental Health Services in [redacted]**
REC reference:	**18/WA/0372**
Protocol number:	**1**
IRAS project ID:	**237661**

Thank you for your letter responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair, Dr K. Craig.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to make a request to postpone publication, please contact hra.studyregistration@nhs.net outlining the reasons for your request.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation [as revised], subject to the conditions specified below.

Conditions of the favourable opinion

The REC favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).

Guidance on applying for HRA and HCRW Approval (England and Wales)/ NHS permission for research is available in the Integrated Research Application System, at www.hra.nhs.uk or at http://www.rdforum.nhs.uk.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of management permissions from host organisations

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database within 6 weeks of recruitment of the first participant (for medical device studies, within the timeline determined by the current registration and publication trees).

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to request a deferral for study registration within the required timeframe, they should contact hra.studyregistration@nhs.net. The expectation is that all clinical trials will be registered, however, in exceptional circumstances non registration may be permissible with prior agreement from the HRA. Guidance on where to register is provided on the HRA website.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Ethical review of research sites

NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	*Version*	*Date*
Copies of advertisement materials for research participants [Poster - GP Practices]	V2	18 March 2019
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Indemnity Certificate]		19 September 2018
Interview schedules or topic guides for participants [Focus Group Questions - Service Users]	V4	18 March 2019
IRAS Application Form [IRAS_Form_19032019]		19 March 2019
IRAS Checklist XML [Checklist_19032019]		19 March 2019
Letter from funder [KESS 2 Agreement]		
Letters of invitation to participant [Invitation letter - Service User]	1	18 March 2019
Non-validated questionnaire [Staff ASD Questionnaire (inc. Debrief Form)]	V4	18 March 2019
Other [Supervisor CV]		27 July 2018
Other [Supervisor CV]		02 August 2018
Other [USW Ethics Approval Letter]		19 September 2018
Other [CI GCP Certificate]		24 November 2017
Other [Debrief Form - Service Users]	V3	09 September 2018
Other [Email confirming the project is classed as research]		10 October 2018
Other [Supervisor CV]		
Other [Service User Demographic Form]	V4	18 March 2019
Other [Permission to Contact Form - Service Users]	V2	18 March 2019
Other [Confirmation of Capacity Form]	V1	18 March 2019
Other [Staff Consent Form - Focus Group]	V4	18 March 2019
Other [Participant Information Sheet - Staff]	V4	18 March 2019
Other [BOARD STUDENTSHIP AGREEMENT]		25 July 2017
Other [CI Valid Informed Consent in Research Certificate]		11 January 2018
Other [Cover Letter for REC Resubmission]		18 March 2019
Participant consent form [Consent Form - Service Users]	V4	18 March 2019
Participant information sheet (PIS) [PIS - Service Users]	V4	18 March 2019
Research protocol or project proposal [Protocol]	V2	18 March 2019
Summary CV for supervisor (student research) [Director of Studies CV]		06 August 2018

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document *"After ethical review – guidance for researchers"* gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The HRA website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/

HRA Learning

We are pleased to welcome researchers and research staff to our HRA Learning Events and online learning opportunities– see details at: https://www.hra.nhs.uk/planning-and-improving-research/learning/

18/WA/0372	**Please quote this number on all correspondence**

With the Committee's best wishes for the success of this project.

Yours sincerely

p.p.
Dr K J Craig
Chair
Email: jagit.sidhu@wales.nhs.uk

Enclosures: "After ethical review – guidance for researchers" *[SL-AR2]*

Copy to: *Dr Louise Bright – louise.bright@southwales.ac.uk*

Appendix 21 - Table illustrating the ethics process undertaken for the current study

Steps undertaken to obtain ethical approval for the study	**Corresponding date**
Study paperwork submitted to the University of South Wales (USW) Faculty Ethics Committee	10th January 2018
Feedback received from USW Faculty Ethics Committee	13th March 2018
Study paperwork amended, and resubmitted to USW Faculty Ethics Committee	12th April 2018
Feedback received from USW Faculty Ethics Committee	24th May 2018
Study paperwork amended, and resubmitted to USW Faculty Ethics Committee	11th September 2018
Approval letter received from USW Faculty Ethics Committee	19th September 2018
IRAS form submitted	4th October 2018
Wales Research Ethics Committee (REC) 1 Meeting	6th November 2018
Feedback received from Wales REC 1	8th November 2018
Study adopted onto the Health Care and Research Wales Portfolio	26th February 2019
IRAS amendments submitted	19th March 2019
Wales REC 1 Approval obtained	26th March 2019
Health Research Authority (HRA) and Health and Care Research Wales (HCRW) Approval obtained	28th March 2019
Approved study paperwork sent to USW for final approval	28th March 2019
Approval letter obtained from USW Faculty Ethics Committee	1st April 2019
The health board confirmed their Capacity and Capability to deliver the study	11th April 2019
Permission to proceed given by USW for study commencement	15th April 2019
Steps undertaken for approval of the non-substantial amendment	**Corresponding date**
Non-substantial amendment submitted to USW Faculty Ethics Committee	7th October 2019
Approval letter received from USW Faculty Ethics Committee for the non-substantial amendment	17th October 2019
Non-substantial amendment submitted for approval by the health board's Research and Development Team to Health and Care Research Wales	21st October 2019

Wales REC 1 approval received for non-substantial amendment	23rd October 2019
No objections (to the non-substantial amendment) letter received from the health board	24th October 2019

Appendix 22 - Cronbach's alpha for ASD Knowledge scale

Reliability Statistics

Cronbach's Alpha	Cronbach's Alpha Based on Standardized Items	N of Items
.923	.932	28

Appendix 23 - Cronbach's alpha for ASD Confidence scale

Reliability Statistics

Cronbach's Alpha	Cronbach's Alpha Based on Standardized Items	N of Items
.958	.957	28

Appendix 24 – Item-Total Statistics for ASD Knowledge scale

Item-Total Statistics

	Scale Mean if Item Deleted	Scale Variance if Item Deleted	Corrected Item-Total Correlation	Squared Multiple Correlation	Cronbach's Alpha if Item Deleted
Q1a	64.2931	147.509	.491	.	.921
Q2a	64.9483	141.489	.528	.	.920
Q3a	64.8621	137.910	.632	.	.918
Q4a	64.8793	142.319	.459	.	.921
Q5a	64.7069	138.737	.697	.	.917
Q6a	65.0172	141.421	.519	.	.920
Q7a	64.4483	141.971	.638	.	.919
Q8a	64.9483	143.524	.409	.	.922
Q9a	64.3621	143.007	.678	.	.919
Q10a	64.5345	142.639	.528	.	.920
Q11a	65.2931	143.544	.382	.	.923
Q12a	65.4483	144.532	.418	.	.922
Q13a	64.3276	145.522	.589	.	.920
Q14a	64.5862	143.335	.481	.	.921
Q15a	65.2931	143.193	.379	.	.923
Q16a	65.2586	142.125	.399	.	.923
Q17a	65.0345	139.929	.586	.	.919
Q18a	65.0345	142.560	.418	.	.922
Q19a	64.3276	143.242	.736	.	.919
Q20a	64.3448	143.739	.677	.	.919
Q21a	64.8966	138.445	.598	.	.919
Q22a	65.3793	143.678	.399	.	.922
Q23a	64.5517	138.322	.755	.	.917
Q24a	64.4310	139.934	.781	.	.917
Q25a	65.3793	141.748	.438	.	.922
Q26a	64.3276	144.014	.671	.	.919
Q27a	64.7414	140.265	.579	.	.919
Q28a	64.4655	143.341	.543	.	.920

Appendix 25 – Item-Total Statistics for ASD Confidence scale

Item-Total Statistics

	Scale Mean if Item Deleted	Scale Variance if Item Deleted	Corrected Item-Total Correlation	Squared Multiple Correlation	Cronbach's Alpha if Item Deleted
Q1b	49.3966	156.980	.705	.	.956
Q2b	50.1207	159.757	.581	.	.957
Q3b	49.9655	156.665	.739	.	.955
Q4b	50.1724	159.022	.620	.	.956
Q5b	49.9483	155.699	.721	.	.956
Q6b	50.1897	161.911	.439	.	.958
Q7b	49.7414	157.458	.691	.	.956
Q8b	50.1724	159.619	.557	.	.957
Q9b	49.5690	154.565	.832	.	.955
Q10b	49.6552	156.651	.616	.	.957
Q11b	50.2241	158.773	.661	.	.956
Q12b	50.1379	156.577	.646	.	.956
Q13b	49.5000	156.289	.754	.	.955
Q14b	49.7931	156.623	.730	.	.956
Q15b	50.3966	162.279	.506	.	.957
Q16b	50.4138	162.913	.464	.	.958
Q17b	50.0690	158.381	.625	.	.956
Q18b	50.1379	161.981	.439	.	.958
Q19b	49.1724	160.215	.571	.	.957
Q20b	49.3448	156.616	.716	.	.956
Q21b	49.8793	156.915	.638	.	.956
Q22b	50.2759	159.326	.626	.	.956
Q23b	49.8793	155.371	.748	.	.955
Q24b	49.6552	155.212	.761	.	.955
Q25b	50.3276	158.259	.670	.	.956
Q26b	49.3448	157.914	.728	.	.956
Q27b	49.9138	154.712	.794	.	.955
Q28b	49.6207	156.766	.703	.	.956

Appendix 26 – One-sample Wilcoxon signed rank test for ASD Knowledge (all participants)

Hypothesis Test Summary

	Null Hypothesis	Test	Sig.	Decision
1	The median of ASD_Total_Score equals 22.40.	One-Sample Wilcoxon Signed Rank Test	.000	Reject the null hypothesis.

Asymptotic significances are displayed. The significance level is .05.

Appendix 27 – One-sample Wilcoxon signed rank test for ASD Knowledge (Therapies)

Hypothesis Test Summary

	Null Hypothesis	Test	Sig.	Decision
1	The median of ASD_Total_Score equals 22.40.	One-Sample Wilcoxon Signed Rank Test	.100	Retain the null hypothesis.

Asymptotic significances are displayed. The significance level is .05.

Appendix 28 – One-sample Wilcoxon signed rank test for ASD Knowledge (Social Care)

Hypothesis Test Summary

	Null Hypothesis	Test	Sig.	Decision
1	The median of ASD_Total_Score equals 22.40.	One-Sample Wilcoxon Signed Rank Test	.033	Reject the null hypothesis.

Asymptotic significances are displayed. The significance level is .05.

Appendix 29 – One-sample Wilcoxon signed rank test for ASD Knowledge (Nursing)

Hypothesis Test Summary

	Null Hypothesis	Test	Sig.	Decision
1	The median of ASD_Total_Score equals 22.40.	One-Sample Wilcoxon Signed Rank Test	.000	Reject the null hypothesis.

Asymptotic significances are displayed. The significance level is .05.

Appendix 30 – Spearman's Rho

Nonparametric Correlations

Correlations

			ASD_Total_Score	ASD_Confidence_Score
Spearman's rho	ASD_Total_Score	Correlation Coefficient	1.000	.685**
		Sig. (2-tailed)	.	.000
		N	58	58
	ASD_Confidence_Score	Correlation Coefficient	.685**	1.000
		Sig. (2-tailed)	.000	.
		N	58	58

**. Correlation is significant at the 0.01 level (2-tailed).

Appendix 31 - Kruskal-Wallis test exploring impact of Occupation Group on ASD knowledge scores

Kruskal-Wallis Test

Ranks

	Occ Group	N	Mean Rank
ASD_Total_Score	Therapies	22	39.84
	Social Care	11	24.59
	Nursing	25	22.56
	Total	58	

Test Statistics[a,b]

	ASD_Total_Score
Kruskal-Wallis H	13.507
df	2
Asymp. Sig.	.001

a. Kruskal Wallis Test

b. Grouping Variable: Occ Group

Appendix 32 – Mann Whitney U test comparing ASD knowledge between Therapies and Social Care

Mann-Whitney Test

Ranks

	Occ Group	N	Mean Rank	Sum of Ranks
ASD_Total_Score	Therapies	22	19.36	426.00
	Social Care	11	12.27	135.00
	Total	33		

Test Statistics[a]

	ASD_Total_Score
Mann-Whitney U	69.000
Wilcoxon W	135.000
Z	-1.998
Asymp. Sig. (2-tailed)	.046
Exact Sig. [2*(1-tailed Sig.)]	.048[b]

a. Grouping Variable: Occ Group

b. Not corrected for ties.

Appendix 33 – Mann Whitney U test comparing ASD knowledge between Therapies and Nursing

Mann-Whitney Test

Ranks

	Occ Group	N	Mean Rank	Sum of Ranks
ASD_Total_Score	Therapies	22	31.98	703.50
	Nursing	25	16.98	424.50
	Total	47		

Test Statistics[a]

	ASD_Total_Score
Mann-Whitney U	99.500
Wilcoxon W	424.500
Z	-3.761
Asymp. Sig. (2-tailed)	.000

a. Grouping Variable: Occ Group

Appendix 34 – Mann Whitney U test comparing ASD knowledge between Social Care and Nursing

Mann-Whitney Test

Ranks

	Occ Group	N	Mean Rank	Sum of Ranks
ASD_Total_Score	Social Care	11	18.32	201.50
	Nursing	25	18.58	464.50
	Total	36		

Test Statistics[a]

	ASD_Total_Score
Mann-Whitney U	135.500
Wilcoxon W	201.500
Z	-.069
Asymp. Sig. (2-tailed)	.945
Exact Sig. [2*(1-tailed Sig.)]	.946[b]

a. Grouping Variable: Occ Group

b. Not corrected for ties.

Appendix 35 – A one-way ANOVA exploring the effect of Occupation Group on ASD Confidence

ANOVA

ASD_Confidence_Score

	Sum of Squares	df	Mean Square	F	Sig.
Between Groups	2338.333	2	1169.167	8.772	.000
Within Groups	7330.787	55	133.287		
Total	9669.121	57			

Appendix 36 – Bonferroni post hoc test

Post Hoc Tests

Multiple Comparisons

Dependent Variable: ASD_Confidence_Score

Bonferroni

(I) Occ Group	(J) Occ Group	Mean Difference (I-J)	Std. Error	Sig.	95% Confidence Interval	
					Lower Bound	Upper Bound
Therapies	Social Care	13.04545*	4.26327	.010	2.5177	23.5732
	Nursing	13.10364*	3.37490	.001	4.7696	21.4377
Social Care	Therapies	-13.04545*	4.26327	.010	-23.5732	-2.5177
	Nursing	.05818	4.17714	1.000	-10.2569	10.3732
Nursing	Therapies	-13.10364*	3.37490	.001	-21.4377	-4.7696
	Social Care	-.05818	4.17714	1.000	-10.3732	10.2569

*. The mean difference is significant at the 0.05 level.

Appendix 37 - Kruskal-Wallis test exploring impact of ASD training on ASD knowledge scores

Kruskal-Wallis Test

Ranks

	ASD Training Undertaken	N	Mean Rank
ASD_Total_Score	No	34	24.18
	Yes	24	37.04
	Total	58	

Test Statistics[a,b]

	ASD_Total_Score
Kruskal-Wallis H	8.230
df	1
Asymp. Sig.	.004

a. Kruskal Wallis Test

b. Grouping Variable: ASD Training Undertaken

Appendix 38 – A one-way ANOVA exploring the effect of ASD training on ASD Confidence

Oneway

Descriptives

ASD_Confidence_Score

	N	Mean	Std. Deviation	Std. Error	95% Confidence Interval for Mean		Minimum	Maximum
					Lower Bound	Upper Bound		
No	34	45.8235	10.17862	1.74562	42.2720	49.3750	28.00	69.00
Yes	24	60.1250	12.10933	2.47181	55.0117	65.2383	39.00	77.00
Total	58	51.7414	13.02435	1.71018	48.3168	55.1660	28.00	77.00

ANOVA

ASD_Confidence_Score

	Sum of Squares	df	Mean Square	F	Sig.
Between Groups	2877.555	1	2877.555	23.727	.000
Within Groups	6791.566	56	121.278		
Total	9669.121	57			